

**AN EVALUATION OF A FAMILY-BASED RESPITE CARE SCHEME
FOR CHILDREN WITH MENTAL HANDICAP**

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To My Parents

I hereby declare that this thesis has been composed by
myself and contains only my own work

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ABSTRACT

The aim of the study is to evaluate Share-the-Care, Lothian's family-based respite care scheme for children with mental handicap and to assess its impact on the lives of children, parents and carers. Prospective interviews took place with 30 parents when they applied to join the scheme and follow-up interviews were conducted some months later. Thirty carers were also interviewed, a postal questionnaire was completed by 22 referring agencies and data collected from agency records.

The study shows that the scheme has successfully met the needs and expectations of a substantial proportion of parents, both by reducing levels of stress and strengthening their ability to cope. However, those who originally presented as experiencing relatively little stress were most likely to receive the service and able to use it with least difficulty. The scheme was also able to place some families who were experiencing greater difficulty in coping, but they required more support in using the service. Most parents identified a range of benefits to the handicapped child from involvement in the scheme, the majority of parents greatly preferring family-based respite care to institutional provision. Nevertheless, homesickness among children emerged as an important issue.

Carers too derived considerable satisfaction from their role, which they tended to perceive in terms of their personal commitment to an individual child or as acting in a neighbourly way towards her parents. However, indications were found that, while the present, semi-voluntary status of carers facilitates the process of sharing care for some parents, by enhancing their trust in the situation, for others it acts as a deterrent, by limiting their ability to exercise choice and control. This finding has considerable implications for present practice and future policy.

Some families remained on the waiting-list indefinitely; others chose to withdraw. It cannot be assumed that family-based respite care is appropriate in all cases. Rather, there is a need to develop a range of services offering choice and flexibility to meet differing needs.

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PART I

Introduction

It has been estimated that between six and seven children in every thousand have some form of severe handicap, and that there are between 89,000 and 126,000 children with disabilities (physical and/or intellectual) in Britain (Robinson, 1984). Between 80 and 90% of these children are living at home with their families. Numerous studies have shown that caring for a child with mental handicap can be an exhausting activity (Wilkin, 1979; Chetwynd, 1985; Pahl and Quine, 1985) and parents have repeatedly identified the provision of respite care as a vital form of support (Carr, 1975; Kendall, 1982).

For many years, respite care has been provided in a variety of residential settings, including mental handicap institutions, the paediatric wards of general hospitals and local authority hostels. The origins of family-based respite care, which was introduced to Britain in 1976, stemmed from a variety of factors. One of the more immediate of these was an unforeseen crisis which arose in a Somerset family in 1974, resulting in their handicapped child being temporarily admitted to a mental handicap institution twelve miles away, because no other facility was available. Strong adverse reaction from local parents and teachers, reflecting a growing awareness of 'normalisation' concepts culminated in a campaign for the provision of an informal local hostel (Crine, 1982). The Social Services Department, however, responded by setting up a pilot project for family-based respite care. This scheme was to become the first of many throughout Britain, which offer short, regular breaks to parents by linking their child to another local family, specially recruited and prepared to provide respite care, usually within their own home. While most schemes would probably describe their principal

objective as the provision of on-going support to parents, an important secondary aim is to offer a beneficial experience to the child as well.

Despite the rapid proliferation of the service, particularly during the 1980s in England and Wales, surprisingly little evaluative research of a critical and independent nature has been carried out. Both Campbell (1983) and Oswin (1984), warning against the dangers of treating respite care as a panacea for all ills, have called for more detailed enquiry. They suggest that the service is based on a number of untested assumptions, for example, that the child is necessarily experienced as a burden by her parents, and that an appropriate form of support is one which hinges on separation. This study, then, aims to address these issues and go some way towards filling the gaps in existing knowledge about family-based respite care.

More specifically, the study seeks to evaluate the effectiveness of Lothian's Share-the-Care Scheme, which started in 1979. It aims to explore the impact of the service on the lives of children, parents and carers. Thus, the focus throughout the research will remain on the perceptions of scheme users.

The thesis is divided into three parts. The first is largely introductory; Chapters 1 and 2 aim to locate the research issues within the wider context of related policy, practice and theory, while Chapter 3 outlines the methodology. Part II (Chapters 4 to 8) focus on the analysis of empirical data. Finally Part III (Chapter 9) summarises the main conclusions of the study and discusses their implications for policy, practice, and future research.

CHAPTER 1

Policy and Practice

Introduction

The aim of this chapter will be to explore the main factors leading up to and influencing the development of family-based respite care schemes for children with mental handicap, in terms of related social policy and practice. In doing so, it will be helpful to be guided by an important distinction, drawn by Pinker (1971) between the 'intellectual' and 'institutional' aspects of social administration. By the former he means those

... ideas, concepts, doctrines and theories which have helped to form the intellectual basis of an academic discipline
(p.48)

but which have also contributed to its 'institutional' dimension, that is:

... a social activity ... a component of the social structure.

Pinker argues that the two aspects are inter-dependent and, lamenting the absence of explicit explanatory theory within the field of social policy, advocates that they be treated in tandem.

The chapter begins by discussing the historical exclusion of children with disabilities from the broad field of childcare policy, suggesting that the development of a more child-centred approach owed much to the wider movement towards normalisation policies and community care for 'the mentally handicapped population' as a whole. It goes on to consider the influence played by a number of social and political factors on care within the community, in both the formal and informal sectors and within the family. I shall then outline the development of family-based respite care as a means of supporting

families and the objectives, principles and operational methods which characterise different schemes. The final part of the discussion will include a descriptive account of the operation of Lothian's Share-the-Care Scheme which, it is hoped, will provide a platform from which to examine, in subsequent chapters, the analytical issues arising from fieldwork.

The Development of Community Care Policies for People with Mental Handicap

The term 'community care' has been widely used to signify a vast heterogeneity of social care arrangements for different individuals and client groups. Walker (1982) offers a useful summary of its original guiding principles. It is a policy which

[aims to ensure] that individuals remain integrated with their own families, friends and neighbours; a social pattern of care in non-institutional settings; the provision of support in the home from a wide range of services and preventive measures to ensure that family breakdown and admission to a residential institution does not occur.
(p.16)

Walker argues, however, that the political durability of the concept lies in its ability 'to encompass the widest range of institutions', while the 'ideal' of creating effective social support networks capable of sustaining the individual within the community, has been subject to constant erosion and compromise, as I shall shortly discuss.

Wilkin (1979) has identified the Wood Committee of 1929 as the precursor of 'community care' policies for people with mental handicap. However, as its proposals remained largely unimplemented for thirty years, it may be more realistic to consider the 1959 Mental Health Act (1960 in Scotland) as the first major landmark in government thinking.

The 'Medicalisation' of Mental Handicap

Following the establishment in 1946 of the National Health Service, people with mental handicap who had formerly lived in 'colonies' under the aegis of local authorities, found themselves in newly-designated hospitals, under a medical banner. It has been argued that the 'medicalisation' of mental handicap in this way was an arbitrary, ill-informed decision based on pragmatic considerations (Gostin, 1982). By considering the needs of people with handicaps alongside those of people diagnosed as mentally ill, the 1959 Act reinforced the concept of mental handicap as an 'illness' requiring treatment, thus seeming to confirm the appropriateness of hospital placement, rather than a learning disability responsive to training and stimulation, and therefore requiring educational input and 'social' care. At the same time, however, the Act gave the majority of in-patients 'voluntary' rather than 'compulsory' status and empowered local authorities to provide daycare and residential services within the community. By failing to make such powers obligatory, however, nor to specify targets for provision, the Act lacked sufficient weight to initiate a substantial shift towards community care.

During the 1960s, increasing dissatisfaction with conditions inside large-scale 'mental subnormality' institutions was fuelled by a series of scandals centred around specific hospitals. The 1969 Report of Enquiry into Ely Hospital, Cardiff, for example, revealed the prevalence of poor physical conditions, serious mismanagement and alarming incidents of staff misconduct at ward level.

Martin (1984), analysing this and other failures of caring which occurred between 1965 and 1980, points to the complexity of the

hospital as a social organisation. Among the 'long chains of interconnected events' leading to the scandals, he identifies the physical and intellectual isolation of the long-stay ward, the dominance of secondary over primary aims, a gradual decline in standards and inadequate in-service training for nurses. A detailed study published in 1969 which examined the quality of life for patients within 78 hospital units and 24 residential homes, again showed widespread cause for concern (Morris, 1969). Public awareness spread and, in particular, there was growing concern about the ability of long-stay institutions to provide a suitable environment in which to bring up children.

The Exclusion of Children with Disabilities from Childcare Policy

For the greater part of this century, children with handicaps have largely been excluded from the broad sweep of social policy in the field of childcare and, as Shearer (1980) and Gostin (1982) have pointed out, historically they have been classified as 'handicapped' first and children second. The 1933 Children and Young Persons Act, for example, which required local authorities to 'board out' all children in care, with the aim of finding a permanent substitute home, nevertheless excluded those with handicaps, many of whom therefore continued to live in 'colonies' or residential schools. Similarly, the Curtis Committee, which might be described as representing a landmark in the humane treatment of children in care, declared those with handicaps to be beyond its remit on the grounds that: '...[they] present different problems, most of which are outside our terms of reference' (Curtis Report, 1946). While the Report strongly advised that separate facilities be provided for non-

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handicapped children in care, so that they were not required to reside alongside adults, those with disabilities continued to be accommodated with handicapped adults. Similarly, following Bowlby's findings on the detrimental effects on children of institutional life and maternal deprivation (1953), the Committee on the Welfare of Children in Hospitals (The Platt Committee, 1959) submitted a series of recommendations intended to meet the emotional needs of children admitted to hospital for medical care. Little attempt was made, however, to address the needs of children with disabilities for whom hospital was home.

Important new ground was broken, however, by Professor Tizard's pioneering work at the Brooklands Residential Unit (1964). The aim of this experimental project was to apply normal principles of childcare, generally regarded as vital in meeting the needs of non-handicapped children, to the care of 16 handicapped and, until then, hospitalised children. A dramatic improvement was found to take place in their intellectual abilities and emotional adjustment. Not only did they develop new social and self-help skills, but they were also observed to become livelier and happier within themselves, starting to behave in a similar manner to non-handicapped children of the same age. Sadly, however, it was some years before Tizard's innovative methods were put into wider practice, despite the appearance of further studies which demonstrated the inappropriateness of a hospital regime to the care of young children (King, Raynes and Tizard, 1971; Oswin, 1971). It has been noted elsewhere that a complex divorce between research and practice has continually hampered the implementation of community care policies (Mittler, 1979). Meanwhile the lives of children with handicaps were

affected by such policies largely to the extent that these were developed for 'the mentally handicapped' as a whole.

Their cause was not well served, however, by the White Paper of 1971, 'Better Services for the Mentally Handicapped', nor by its Scottish counterpart, 'The Blue Book' (1972). While proposing a 50% reduction in hospital beds for adults, 'Better Services' envisaged that childrens' beds would be reduced by only one-seventh. Again, while apparently favouring the location of childrens' facilities within small domestic units, separate from adult provision, the Paper also stated:

There may occasionally be situations where, by suitable planning, accommodation for children and adults can be provided in an acceptable way on one site.
(Chapter 5, para.249)

Furthermore the Paper drew a distinction between 'severe' and 'mild to moderate' handicaps, envisaging that children who fell into the former category would continue to require long-term hospital care. Tyne (1982) has commented, 'This fundamental structural division has dogged attempts at change throughout the seventies and into the eighties' (p.145).

At the same time, however, the White Paper outlined a 25-year plan, aiming to develop community, residential, daycare and domiciliary services, and to run down the role of hospitals. But it was cautious in making provision: 'The government will play its part, but the main responsibility lies with the local authorities themselves'. Although target numbers were set for building-based services, there were none for more innovatory provision, nor for staffing levels. Jaehnig (1979) has summarised the Paper as 'a political compromise' which lacked the underpinning of concrete provision required to translate policy into practice.

The Concept of 'Normalisation'

However, 'Better Services' also laid down 15 general principles for good practice, stressing the importance of the handicapped person taking his or her own place in society and having right of access to mainstream medical, social and occupational facilities. Although the Paper did not specifically outline a policy of 'normalisation' as such, nevertheless these principles foreshadowed what was to become a highly influential factor on subsequent policy, including the development of family-based respite care.

The concept of normalisation originated in Scandinavia. Bank-Mikkelsen, Director of the Danish Mental Retardation Service, played an instrumental role in having the principle enshrined in legislation as early as 1959, its main objective being defined at that time as 'to create an existence for the mentally-retarded as close to normal living conditions as possible' (Bank-Mikkelsen, 1980, p.56). Bank-Mikkelsen's conception of normalisation has been criticised, however, for its emphasis on outcome rather than process, which may lend legitimacy to the idea of the 'good institution' (Wolfensberger, 1980).

Another early exponent of the principle was Nirje, Director of the Swedish Association for Retarded Children, who, in 1970, defined normalisation as:

... making available to the mentally subnormal patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.
(p.62)

Nirje suggested that people may contend with three 'layers' of handicap: their innate disability, a superimposed or acquired one (such as behavioural disorder) and their own awareness of being

different. However, he also stressed that normalisation was not designed to make the handicapped person 'normal' but to ensure his or her right to enjoy a similar lifestyle to the rest of society; for example, to experience normal daily routines and rhythms, to have bisexual contacts and to make choices and decisions regarding their own lives. The implications of this principle in relation to children with disabilities involve a recognition, firstly, that they share the same emotional needs and feelings as all other children, irrespective of handicap, and, secondly, that they should be exposed to the same experiences, such as living within a family environment, participating in one-to-one relationships marked by affection and consistency and receiving a high quality of educational input. Thus, the movement towards normalisation within policy and practice was to have a fundamental effect on reversing a long-standing phenomenon whereby children were primarily perceived as part of 'the mentally handicapped population'.

Difficulties in Implementation

Nevertheless, it was a slow and, in some ways, unsatisfactory process. A study group appointed by the Secretary of State for Social Services in 1974 found that, out of a total of 8,500 children with mental handicaps in residential care in England and Wales, 6,500 lived in hospitals, 1,000 in local authority homes, 900 were in voluntary or private homes and only 100 placed in foster care (DHSS, 1974). The plight of those resident in long-stay hospitals was graphically illustrated by Oswin (1978). Following detailed observation she reported that children received on average one hour of physical care and five minutes of 'mothering' within any ten-hour period and, furthermore, while by no means cruelly treated, and

physically well cared for, their basic emotional and learning needs remained sadly neglected. As a result, many children had become lonely and withdrawn, developing bizarre and self-absorbing behaviours, as a means of compensation.

Various reasons may be cited for the continuing failure to translate policy into practice during the 1970s, ranging from the political and economic to the administrative and cultural. Wolfensberger (1972) had been instrumental in widening both knowledge and debate about normalisation and in extending the principle to other groups of 'devalued' persons. He argued that society has always sought to eliminate those whom it views as deviant, and to segregate them from the majority. Ryan and Thomas (1980), tracing the historical development of attitudes towards people with mental handicap, clearly demonstrate the durability of a perception which views them as a social threat requiring containment. During the Lutheran age, for example, handicapped babies were thought to be the offspring of the Devil and their mothers, witches. With the rise of industrial society, the presence of disabled family members, incapable of economic activity and perhaps requiring the provision of full-time care by another relative, constituted an unacceptable financial burden. In the early twentieth century, people with mental handicap were believed to be sexually promiscuous and thus 'morally defective'. The Board of Control recommended in 1930 that such individuals should be prohibited from marriage, due to: '... the racial danger of breeding from tainted stock'. Ryan argues that even today, the current social and political emphasis on values such as individual achievement, self-sufficiency, competitiveness and economic productiveness militates against the development of positive

public attitudes towards those with disabilities, who may be unlikely to excel in these areas. In short, public opinion is clearly an important factor in the development of community care and one which has not always facilitated attempts at integration. It has not been uncommon, for example, for local residents to object to the location of facilities within their own neighbourhood. A similar reaction may now be identified in relation to people suffering from Aids.

Bayley (1973) has suggested that the impetus towards community care during the 1970s was largely fuelled by widespread dissatisfaction with institutional provision rather than a sound knowledge of the benefits of community care and how best to achieve them. The resistance of much of the medical profession, and its lack of accountability, has also been identified as a crucial factor (Mittler, 1979). Furthermore, within the medical framework, mental handicap has traditionally been accorded a low priority. It has been estimated, for example, that during the 1970s there were only 140 psychiatrists in Britain specialising in the field, yet they carried responsibility for at least 50,000 in-patients (Walker, 1982). The proportion of the NHS budget allocated to the care of these residents has traditionally been low (Abel-Smith, 1976). Townsend (1974) has pointed to attempts on the part of both Labour and Conservative administrators to follow contradictory policies simultaneously. Following the disturbances at Ely and a number of other institutions, for example, a programme of upgrading and renovating hospital premises had been implemented.

Recent Developments

Nevertheless, some important advances have taken place since 1970, not only in the development of small-scale residential and

training facilities for adults, but also in policy and practice affecting children. The Education (Handicapped Children) Act, 1970, by bringing this group into the mainstream educational system, not only acknowledged their potential for development, but also guaranteed parents a form of daily respite, thus enabling them to care for their children at home. The provision of new benefits under the social security system had a similar effect. Thus, the number of children living in hospital in England and Wales dropped from 7,100 in 1969 to 2,839 ten years later (Oswin, 1984). A related development was the role of advocacy by and on behalf of people with mental handicap and the growth of parents' pressure groups, such as Mencap and Exodus. Again, there was increasing realisation among professionals that if normalisation was to succeed, parents must be involved as partners and colleagues (Mittler, 1979).

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Official acknowledgement that children with mental handicap had certain fundamental needs, irrespective of disability, first came from the Court Report (1976) which proposed the establishment of an integrated child health service, and from the National Development Group (1977a) set up by Barbara Castle to advise on policy matters in England and Wales. However, the concept of family support was not a new one. The Seeborn Report (1968) had stated:

We are convinced that if local authorities are to provide an effective family service, they must assume much wider responsibilities for the prevention, treatment and relief of social problems ... Much more ought to be done, for example, for the mentally handicapped.
(Chapter VII, para.139)

It will shortly be argued, however, that the implementation of family support services has been limited, respite care being a significant exception.

A number of policy documents have been issued by the DHSS since

1980, among which 'Care in the Community' attracted considerable attention (1981). It created more favourable conditions for securing joint finance and gave greater encouragement to health and local authorities to find their own ways of moving people into the community. The Disabled Persons Act (1986) has been widely welcomed as a means of co-ordinating and improving the delivery of services. It does not, however, introduce any new ones and its phased implementation has created some difficulty for local authorities in terms of forward planning. The relative affluence of the 1960s has given way to the recession of the late 1970s and 1980s, leading to massive cuts in public expenditure. The establishment of a comprehensive programme of community-based services, offering real choice within a range of quality provision, would require, initially at least, a huge injection of capital. However, the Griffiths Review, set up by the Government to examine ways of improving the quality of community care, is unlikely to recommend any increase of existing funds (Chamberlain, 1987). Meanwhile, voluntary organisations are heavily relied upon to lead the way in providing innovatory services ('Better Services', Chapter 7, para.281). The Audit Commission (1986) has expressed deep concern about the recent rapid expansion of private and voluntary residential provision, fuelled by the availability of supplementary benefit payments. The Commission argues that the closure of long-stay hospitals creates a 'window of opportunity' for the establishment of effective community-based services. If this is not taken,

The result will be a continued waste of scarce resources and, worse still, care and support that is either lacking entirely, or inappropriate to the needs of the most disadvantaged members of society.
(p.5)

Important exceptions in England have been the £175,000 DHSS grant awarded to Mencap in 1982 and the 'Pound for Pound' scheme, whereby every pound raised by the voluntary sector towards the cost of moving patients into community placements, is matched by a pound from central government. The current situation in Wales is radically different, following the implementation, in 1982, of a ten-year plan which aims to provide a comprehensive package of services targetted at local population groups of not more than 100,000 each. Scotland, however, is lagging behind in a number of respects. She has a higher rate of hospitalisation and a lower level of local authority residential accommodation than either England or Wales (Baker and Urquhart, 1987). Less resources have been allocated to Scotland and fewer political initiatives taken in relation to people with mental handicap (Farquharson, 1984). This pattern is echoed in the provision of respite care schemes for children. In 1984, the self-help organisation Contact-A-Family was able to identify nearly 60 such schemes in England and Wales, compared to just one in Scotland. Evidence suggests that the disparity today is even greater.

Summary

The present situation in relation to children with mental handicap may be summarised as follows. While for many years they were excluded from the broad sweep of childcare policy, more recently their right to enjoy the same quality of life as any other children has become widely accepted. Three main factors account for this shift in perception: a realisation of the damaging effects of institutionalisation, the wider movement towards community care policies for 'the mentally handicapped' as a whole and thirdly, the principle of normalisation. It is now recognised that children

should be brought up within a normal family environment wherever possible and, indeed, of the 89-126,000 children with disabilities in Britain today, well over 80% are living at home with their families.

However, despite a widespread adherence at both local and central government level to concepts of family support and preventive work, the development of such services within the community has proved a slow and, in many aspects, unsatisfactory process, to the extent that care within the community has been characterised as care within the family, provided mostly by women (EOC, 1982; Finch and Groves, 1983). Nor should this situation be viewed in isolation from a number of broader, but related, social and political factors which, because they have significant implications for the development of family-based respite care, I shall now discuss in some detail.

The Socio-Political Context

(i) The Formal Sector : The Absence of Family Policy

The division of responsibility between the state and the family for the care of its dependent members is constantly shifting, according to the prevailing economic and ideological climate (Glendinning, 1983). As Walker (1982) has demonstrated, the state's most effective means of exerting control over family life, should it wish to maintain the status quo, may be through a policy of non-intervention. Such an approach would be facilitated by the historical absence in this country of a comprehensive family policy or, indeed, any serious attempts to formulate one. The Welfare State, for example, is largely designed to meet the needs of certain groups of individuals who exhibit a common characteristic, such as 'the elderly' or 'the unemployed'. Thus, services are targetted at selective groups rather than being provided on a universal basis.

Only families considered to be at risk, such as one-parent families, are generally included; only children whose parents receive supplementary benefit are entitled to free school meals, for example. One notable exception to this generalisation is child benefit, paid to all parents of children aged under 16.

Maternity
Grant?
1969

Considerable emphasis has been placed, however, on helping families to help themselves. The Seeborn Report (1968) explicitly stated that services should aim to strengthen the capacity of families to care and only when that breaks down should they substitute for them. Likewise, the Court Report (1976), on the development of child health services, observed:

We have found no better way to raise a child than to reinforce the abilities of his parents to do so.
(p.2)

It has been argued that the present administration, by treating the family as something of a fragile being 'in need of protection rather than active support' has done little to alter its basic structure and much to maintain the traditional roles of individual members (Walker, 1982). Certainly, current government thinking strongly emphasises, as a social and moral good, the central role of the family within society and the responsibility of parents for all aspects of their children's upbringing, bar academic education. Indeed their 'laissez-faire' approach is an integral part of the New Right's ideological commitment to such values as individualism, self-reliance and competition, values which, it may be argued, are not conducive to the development of community care within either the formal or informal sectors. The Prime Minister has put it this way:

...But it all really starts in the family, because not only is the family the most important means through which we show our care for others. It is the place where each generation learns its responsibilities towards the rest of society. I think the statutory services can only play their part successfully if we don't expect them to do for us things that we could be doing for ourselves.
(Thatcher, 1982)

One result of this policy may be that parents looking after handicapped children at home will feel inhibited from seeking external support, from the informal or formal sector, because to do so would seem to represent an abdication of their proper responsibilities and/or an admission of inadequacy. Indeed, these attitudes have been found among parents of non-handicapped children (Backett, 1982; Hill, 1984). Voysey (1975) suggests that the concept of family life has become inextricably linked to certain 'socially desirable' values, such as respectability and acceptability. She argues that parents of handicapped children, whose family experiences may differ from 'the norm', nevertheless strive to present a 'normal' facade, for fear of appearing deviant. This strategy may discourage them from seeking out the very services which, subject to their availability, might lessen their sense of isolation. Instead, they are driven into an increasingly 'privatised' and unsupported family life.

An end result of this situation, especially in times of economic recession and cutbacks in public expenditure, is that increasing prioritisation is likely to favour those families who visibly cannot cope and thus cater primarily for those who need total substitute care. Wilkin (1979) in a study of 120 families caring for a handicapped child at home, half of whom were awaiting admission to long-term hospital care, notes that the personal social services perceived their role largely in terms of crisis management. It was

only when families could no longer cope without support that they were considered eligible to receive it.

Packman (1981) following a similar argument in relation to childcare policy, predicts that the 1980s will be a decade of increasing polarisation between: 'community involvement, participation and prevention on the one hand and extreme measures of removal and control on the other' (p.196).

(ii) **The Informal Sector**

The Barclay Report (1982), discussing the future development of the personal social services, placed great emphasis on the potential for partnership between the formal and informal sectors, the latter term being used to signify unofficial support networks, which actively sustain the individual within the community and consist of relatives, friends and neighbours. However, it might be argued that radical changes have taken place over recent years within the structure and nature of 'the family' and 'the community' which militate against their ability to support dependent members, although Laslett (1971) has suggested that the commonly-held perception relating to the existence of 'extended families' prior to the Industrial Revolution is a fallacy. The dominant type of contemporary British family has been described as '... nuclear, usually two generational, highly mobile and [consisting] more and more of two working spouses' (Moroney, 1976, p.30). High levels of unemployment, however, increase the likelihood that at least one partner will not be in full-time occupation.

Wilkin (1979) accepts the 'modified extended family' as typical, noting that individual family units, while maintaining considerable autonomy, are still dependent to some extent on other units within

the wider network. However, he cites changes in the level and nature of support on offer. Increased mobility has distanced families geographically; greater social mobility may distance them psychologically. Similarly, post-war housing policies, as has been well documented elsewhere (Young and Willmott, 1957; Klein, 1965) have led to the break up of long-established working-class communities which provided continuous mutual support on both emotional and practical levels. Given this range of factors, it is not surprising that a number of studies have shown that the contemporary family receives very little assistance in childcare from their neighbours, and less from friends (Backett, 1982; Osborn, Butler and Morris, 1984). Regular practical assistance from the extended family is also limited, and likely to be provided mostly by the couple's own parents. These findings have also been made in relation to families with handicapped children (Wilkin, 1979; Kendall, 1982; Pahl and Quine, 1984). Patterns of support differ, however, among families from ethnic minority groups.

(iii) **Care Within the Family**

The activity of caring for others, often associated with qualities such as patience and self-sacrifice, has long been culturally defined as 'natural' to women: 'reflecting both their biological nature and psychic needs ... It becomes the defining characteristic of their self-identity and their life's work' (Graham, 1983, p.18).

Graham argues that most research into the nature of caring has tended to focus on its emotional and psychological aspects, rather than questioning the underlying premise that women should be expected to engage in unpaid domestic labour, often involving arduous physical

work. She proposes that the dual aspects of caring - the emotional and practical - be analysed together, since caring itself is experienced as 'a labour of love'.

A link has also been demonstrated between the ideological and economic dimensions of caring (Ungerson, 1983). The social security system has long discriminated against women. Up until 1986, for example, married or cohabiting women were not eligible for Invalid Care Allowance, even if they had given up work to look after a disabled person. Similarly, lack of childcare provision, for example, in day nurseries, and recent changes to maternity benefits may conspire to keep women away from the workplace and within the home.

A number of studies over recent years have suggested that marriages are becoming increasingly egalitarian in nature (Young and Wilmott, 1973; Fletcher, 1977). Oakley (1974), on the other hand, found that only a minority of husbands actively participated in housework. By asking detailed questions identifying specific tasks and the amount of time regularly allocated to each by either partner, she found that husbands were more likely to help with childcare rather than housework, 25% having a high level of participation in childcare and 45% a low one. Fathers were mainly expected to play with children: '... to take [them] off the mothers' hands occasionally at weekends, to be generally interested in their well-being and to take over in times of crisis' (p.155). Oakley concludes that, while marriages have become more egalitarian in terms of decision-making and shared leisure pursuits, in most cases overall responsibility for childcare and household tasks rests very much with women. Similar findings were made by Osborn, Butler and Morris

(1984) in their study of 13,315 families who had five-year old children in 1975. Backett (1982) reports that not only did fathers carry considerably less responsibility than did their wives for both childcare and housework, they also over-estimated the real extent of their contribution.

These studies have been concerned with parents of non-handicapped children. Caring for a child with disabilities is likely to involve a much greater degree of bodily care (feeding, toileting and bathing, for instance), arduous physical work (such as lifting a heavy child) and sometimes constant supervision, all of which may continue for many years. Despite these factors, many studies have shown that, again, in the vast majority of cases, it is mothers who carry a large proportion of this responsibility (Glendinning, 1983; McCormack, 1978; Kazak and Marvin, 1984). Pahl and Quine (1984) report that 'very little housework was performed by fathers or siblings'. For example, 36% of fathers never washed up; 38% never shopped; 50% never cleaned; 61% never cooked and 84% never washed any clothes. In relation to the care of the handicapped child, the authors report that only 19% of fathers helped with feeding on a daily basis; 15% with nappies; 12% with toileting; 10% with dressing and washing, while 11% regularly got up at night to attend to the child. Returning to Graham's point about the interdependence of practical and emotional aspects of caring, it may not seem surprising that a high degree of association has been found between lack of practical support and the incidence of emotional stress among mothers (Pahl and Quine, 1984; Bradshaw and Lawton, 1978; Butler et al. 1978).

Summary and Conclusions

To summarise thus far, I have argued that a number of factors within the present social and political climate - a non-interventionist family policy, the selective nature of services, the structure of the nuclear family and the erosion of long-established communities - have all contributed to a failure of community care at both the formal and informal levels. Considerable evidence has emerged that, within the family, women continue to carry most responsibility for housework and childcare tasks.

Given this scenario, it is not surprising that numerous studies have shown that the presence of a handicapped child can create or exacerbate stress within the family (Carey, 1982; Chetwynd, 1985; Hunter, 1980). This area will be explored in greater detail in Chapter 2, as part of the theoretical framework for the present research. For the time being, my interest in these findings lies in their implications for the development of family-based respite care. When asked what type of service would be most useful in reducing or preventing stress, parents have repeatedly identified respite care as a priority (Bolton Community Health Council, 1983; Turnbull, Brotherson and Summers, 1984; Lloyd-Bostock, 1976). Other studies have identified a link between a low incidence or absence of stress and the availability of regular breaks (Chetwynd, 1985; Pahl and Quine, 1984). It is now time to trace the development of family-based respite care as an important means of supporting parents.

The Development of Family-Based Respite Care

Respite care for children with disabilities has been defined as:

... the arrangements whereby a handicapped child is looked after in a place other than his own home for a period of time which includes at least one night but does not exceed three months
(Oswin, 1984, p.7)

and again

Respite services offer help to families who have a handicapped child at home. The period of help can vary from a few hours to several weeks, and the location can be the home of another family, a residential establishment or the child's own home.
(Robinson, 1984)

For the purpose of the present study, family-based respite care might be described as:

A service which offers parents a break from caring by linking them to another local family (or individual), especially recruited and prepared for this purpose, in whose home the handicapped child regularly spends short periods, ranging in length from a few hours up to a fortnight.

Kendall (1982) suggests that the concept of respite care is a relatively new one, having arrived in Britain from the United States during the 1970s. The name may have been new, but the practice was not. Until 1952, all admissions to psychiatric hospitals were supposed to be formal, but before that date at least one institution - Fountain Hospital in London - had provided short-term care for children in order to give their parents a break (Oswin, 1984). Circular 5/52, however, allowed for informal respite admissions to hospital, up to a maximum length of two months (Ministry of Health, 1952). Throughout the 1950s and 1960s, children were receiving respite care in a variety of medical settings - from the paediatric units of general hospitals to the long-stay wards of 'subnormality' institutions. The 1963 Children and Young Persons Act empowered

local authorities to give appropriate 'assistance' to parents in order to prevent their children being received into care but for several years to come it was the health service which continued to be the main providers of respite care. One of the most innovative projects at this time was the Honeylands Unit, established in an Exeter hospital by Professor Brimblecombe, which offered a range of family support services including respite care.

As mentioned previously, a number of studies were published during the 1970s which established parents' felt need for respite (The Younghusband Report, 1970; Carr, 1975; Bayley, 1973; Hewett, 1970). Similarly, several policy documents recommended the development of the service. The 1976 Court Report, for example, suggested that greater availability of respite care might reduce the number of admissions for long-term care. The Peters Report (1978) commented:

short-term care has much to commend it; it helps to cope with emergencies; it can relieve intolerable strain created by illness or other crisis in a family; it can provide relief to a family ...
(para.6.63)

and recommended that, along with residential short-term care, night sitters and home helps should also be made available. Similar views were expressed in the Jay Report (1979) and by the National Development Group (1977a, 1977b), who also noted that hospitals did not constitute a suitable setting in which to provide respite care for children.

The emergence of family-based respite care must also be seen within the context of several factors which have already been discussed in some detail; the realisation of the damaging effects on children of institutionalisation; the wider movement towards

community care and normalisation policies and a more child-centred approach to the care of children with disabilities. At the same time, growing awareness of the stress faced by families caring for such a child at home, the rise of parents' pressure groups and the concept of family support all played a part. Other important factors, which have not yet been explored, were related developments within the fields of fostering and adoption.

Although family-based respite care is a relatively recent phenomenon in Britain, complementary and substitute care of children has been practised for hundreds of years. The origins of present-day fostering have been traced back to the apprenticeship of poor law children in the sixteenth century (George, 1970) and its history since then has been well documented (Packman, 1981). In the past 10 to 15 years, however, several significant changes have taken place which have a direct bearing on the development of respite care for children with disabilities. These are: the type of children considered eligible for fostering and adoption, the increasing 'professionalisation' of the task and the emergence of short-term and specialist fostering.

Recent social and demographic changes have led to a decreased availability, for adoption or fostering, of children aged under five, particularly healthy babies, with the result that greater attention has been paid to the needs of other groups of children previously considered virtually impossible to place. At the same time, children born with severe disabilities now have much higher chances of survival and if their natural parents are unable to care for them, it is recognised that they would benefit from living in a permanent substitute family rather than in residential care. Following the

example of American agencies such as 'Spaulding for Children' in Michigan, the London-based 'Parents for Children', successfully demonstrated the ability of these children to adapt to new families as well as the willingness of many British couples to parent them. Specialist fostering and adoption services of this type are now provided by a variety of voluntary and statutory organisations (see, for example, Macaskill, 1985).

It has been recognised that foster and adoptive parents caring for these children are likely to differ in certain respects from 'traditional' foster parents (Wolfarth et al. 1985). For example, they may require specialist knowledge and skills and therefore receive fuller training. A parallel development has been the emergence of treatment or specialist fostering, whereby foster parents care for other groups of 'hard to place' youngsters, such as persistent truants, often working to individual contracts which specify certain therapeutic tasks and treatment goals (Shaw and Hipgrave, 1983). A key factor in the success of such placements is the development of good working relationships with natural parents to whose care the youngsters are to be restored (Aldgate, 1980). The theoretical issues arising from the literature on foster care will be examined in Chapter 2 but, in terms of policy and practice, the developments described above may be viewed as important precursors of family-based respite care.

The first specialist fostering scheme was introduced to Reading in 1971. Five years later, the first family-based respite care scheme in Britain was established in Somerset, shortly followed by Leeds. Since then the service has expanded rapidly. It has been estimated that, by 1979, at least 14 schemes existed in England

(Kendall, 1982). The first Scottish scheme, Lothian's 'Share-the-Care', also began in that year. A survey carried out in 1984 by Contact-A-Family identified 64 respite care schemes (although not all family-based) in Britain. Since August 1983, parents have been able to continue claiming Attendance Allowance during periods of respite for up to four weeks. More recently, schemes have been introduced for other client groups, notably the elderly. The House of Commons Select Committee on Social Services (1984) recommended they be extended to cater for children at risk as a preventive measure.

The Objectives, Principles and Operation of Family-Based Respite Care

Despite the rapid proliferation of family-based respite care schemes throughout the country, the service has largely developed in an *ad hoc* and unstructured manner, in isolation from any coherent social policy or national guidelines (Oswin, 1984). Inevitably this has led to considerable variation in the character of individual schemes. Nevertheless, certain broadly-based objectives and principles can be identified which are common to most.

As previously outlined in the Introduction, the principle aim of family-based respite care is to provide ongoing support to parents by offering them a regular break from the caring role. Another objective, usually presented as secondary, is to provide a beneficial experience for the child, by placing her in a family environment. A third, and related, aim is to prevent or reduce the need for admissions to institutional care, be it in the short-term, for respite, or the long, should parents' abilities to cope with the child break down due, for example, to inadequate support. Clearly these objectives are based on certain implicit premises, namely, that parents will benefit from a break which involves physical separation

from the child and that regular respite will reduce levels of stress, thus enhancing parents' ability to continue caring. Evidence does exist to support these claims in a general sense (Pahl and Quine, 1984; Chetwynd, 1985), although in relation to the organisation and provision of respite care they have also been brought into question (Campbell, 1983; Oswin, 1984).

While most schemes would probably endorse the above objectives, some have identified additional aims. In East Suffolk, for example, public education was seen as an important goal (Ayres and Lewis, 1983), while in Cornwall the task of helping parents 'let go' of their children was identified (Caudrey, 1984). Again, while many schemes are careful to avoid presenting family-based respite as a form of crisis intervention, others such as Coventry (1983) have described it as just that.

Clearly the service is intended to reflect principles of normalisation, community care and good childcare practice. Unlike fostering, it does not involve any statutory admission into care, but can operate informally in England under Section 21 and Schedule 8 of the National Health Service Act (1977) and, in Scotland, under Section 12 of the Social Work (Scotland) Act (1968). Thus the schemes are designed to be as informal and accessible as possible and parents' use of the service should be entirely voluntary. Research has repeatedly shown that, in order to be useful and acceptable, support must be offered to parents in a way which involves them as partners and which can be readily accommodated within their existing coping strategies (Bayley, 1973; Hunter, 1980; Schilling, Gilchrist and Schinke, 1984). Flexibility and the capacity to adapt to meet

individual and changing needs are also designed to be key features of the service.

Most schemes operate on a universal, as opposed to a selective, basis, in order to avoid the risk of labelling families or creating stigma. However, the Haringay Scheme has taken the unusual step of grading children according to the severity of their handicaps, carers' payments varying accordingly (Pont, 1983).

Variations between individual schemes become more apparent in relation to their methods of operation. In the following discussion, particular attention will be paid to Lothian's 'Share the Care'. It is hoped that this account of the practical arrangements for its operation will set in context the analytical issues arising from fieldwork.

At a superficial level, differences between schemes are illustrated in the wide range of names chosen to denote them. Some have adopted 'catchy' titles intended to reflect the informality and accessibility of the service, such as 'Home from Home' (Manchester), 'Give Mum a Break' (Bradford) and 'Time Out' (Leeds). Others have maintained a more conventional tone, such as 'Short Term Fostering for Mentally Handicapped Children' (Somerset) and 'The Family Relief Scheme' (Hounslow). While the majority of schemes are run by local authority social services departments, some are based around special schools and at least one is run within a hospital, organising family-based respite for children who are long-stay patients (Powceby and Jowett, 1985). Several schemes are run by voluntary organisations, including Barnardo's and the P.A.C.T. project in York (Bird, 1982). Although local authorities carry primary responsibility for funding, a number of English schemes have secured joint funding with local

Area Health Authorities. In 1984, the West Glamorgan Scheme was granted three years funding from the Welsh Office under the Local Authority Urban Programme. In other cases, national charities have contributed towards costs as, for example, Mencap did with the Merton Scheme. Again, staffing arrangements vary between different agencies. While some have specialist workers employed solely on the respite care scheme, which is the case in Lothian, elsewhere these duties are absorbed by adoption or fostering staff. In Avon, generic social workers are required to act as 'key workers' in linking and supporting families while also carrying a caseload (Robinson, 1986).

Perhaps the most significant difference between schemes throughout the country relates to the status of carers (that is, the 'respite carers'). In some cases, such as the Avon Family Support Service, they act as professional, paid workers and receive a regular salary. In others, carers are purely volunteers: the P.A.C.T. Scheme in York makes no payment. In several cases carers lie, perhaps somewhat uneasily, between the two. In Lothian, carers might be described as having a 'semi-voluntary' status. They currently receive £9 per calendar date that the child spends with them and may also claim petrol expenses. The Department also undertakes to provide any special aids or equipment required. They do not, however, receive any retainer. No charge is generally made to the parents. One notable exception, however, is the Suffolk Scheme where parents were not only asked to pay their carers direct, but also to negotiate the sum between themselves. Not surprisingly, perhaps, this arrangement led to considerable difficulties (Goodenough, 1984).

Individual projects also have differing operational norms. It is common for carers to be linked to only one child in order to

facilitate the development of good relationships. The majority of Lothian carers are 'matched' to one family, although a few are linked to two. However, where carers act as professional workers, they are expected to take a higher number of children. A recent evaluation of the Avon Family Support Service (Robinson, 1986) reports that carers were linked to an average of eight children each, but in one case the number was 15, resulting in a variety of problems for all concerned. It is common for guidelines to be issued regarding the maximum amount of time a child should spend with their carer throughout the year. In Lothian it is six weeks. Most schemes have an upper age limit of 18 or 19 and comparable provision for adults is limited. The Lothian Scheme caters for 0-16 year olds. While a few schemes, such as that in Haringay, aim to include children with physical disabilities only, the majority cater specifically for those with mental handicaps, many of whom have additional physical disabilities or associated medical disorders.

A number of agencies have reported that carers applied to join their scheme as a result of recruitment campaigns and publicity material (Pont, 1983; Walton and Stanton, 1986). Others have found a low level of response to these methods and suggest that word-of-mouth has been more effective (Macey, 1981; Banks, Grizzell and Strettle, 1984). It has been noted that those who come forward to act as carers often have previous experience of people with mental handicaps, in either their personal or professional lives (Bird, 1982; Powceby and Jowett, 1985). Most schemes organise a series of group preparation or training sessions for carers, consisting of three to six weekly meetings. These may involve input from professional staff about aspects of handicap, talks given by

established carers or parents using the scheme, films and videos, and visits to local agencies or special schools. Some organisations, including the Northumberland Short-Stay Family Care Scheme, emphasise self-selection as an important part of this process (Smith and Smith, 1979). In Lothian, carers are usually encouraged to attend group training along these lines, but alternatively or in addition, may be prepared on a more individual basis at home. Two personal references are sought and checks are made with the police, GPs and the local social work department. *Known?* It is sometimes necessary for applicants to be counselled out.

Once carers in Lothian have successfully completed preparation, social workers are responsible for linking or 'matching' them to a suitable family. Families are referred to the scheme from a variety of sources or may refer themselves. Their application form consists of a 'child profile' which outlines details of the family's circumstances and the child's skills, personality, behaviour, likes, dislikes, and so on. Important considerations for matching include physical locale, the strengths, limitations and preferences of individual carers and the size, age, sex, and disability of the child. Social class factors and the personalities of carers, parents and child may also be significant. It is sometimes possible to offer carers a degree of choice, by outlining a number of child profiles, but because demand outstrips supply, parents are not given a similar choice at this stage. Once a possible child has been identified, the carers meet that child at his or her school. This takes place without the parents' knowledge, in order to prevent the risk of hurt feelings should the carers decide against proceeding further. Such an outcome is unusual, however, and the next step is for the social

worker to take the carers to visit the family at home. This is usually followed by a return visit by the family to the carers' home. Efforts are made to include all family members on both sides in these visits, to exchange important information about the child and to discuss expectations on both sides. Either party may decide against proceeding further at any point in this process, in which case an alternative match would be sought. Otherwise, the child would begin to spend time at the carers' house, probably unaccompanied by her parents, at first perhaps for a few hours but usually building up to an overnight or weekend stay. It is not expected that children would stay with their carers for longer than a fortnight at once, unless exceptional circumstances prevail.

Again, other schemes operate different matching procedures. Those which have adopted a more 'laissez-faire' strategy, whereby parents are expected to take considerable initiative in making initial contact with carers, or where the social worker is not present during introductory meetings, have encountered some difficulties (Caudrey, 1984; Goodenough, 1984). The importance of sound matching for the future success of individual links and for the scheme as a whole has been emphasised (Bryant, 1984).

It has been suggested by a number of commentators that, once the initial visits have taken place, social workers can withdraw to the background and monitor the match from a distance (Pont, 1984; Bryant, 1984). Parents are then free to make their own arrangements for breaks by contacting the carers and asking them to look after the child on specific dates. It is thought that this method of negotiation allows parents to exercise a maximum degree of choice and control. The development of friendly relationships between parents

and carers is generally seen as both a prerequisite and catalyst of this process (Oswin, 1984). This arrangement can be contrasted to that which exists in a number of residential units, whereby parents may be required to book periods of respite months in advance or may only be offered short-term care in a pre-determined package (Bolton C.H.C. 1983). On the other hand, several family-based schemes have reported that parents may experience considerable difficulty in asking carers to take their child. Caudrey (1984) suggests this ambivalence may be linked to certain features of service delivery or the nature of individual family dynamics. Wisdom (1982) has commented that sharing care can be a 'painful and difficult' experience. These themes will be explored in greater detail in Chapter 5.

The level of support offered to carers and parents varies considerably between different schemes. Some, including Lothian, organise support and discussion groups for scheme participants. Social workers in the Camden 'Parent to Parent' Scheme make regular home visits and hold monthly group meetings, as well as organising workshops and social events. The P.A.C.T. Scheme in York seeks to involve its members in decision-making about policy and future development of the scheme through membership of a Management Committee.

The central Share-The-Care team in Lothian (which currently consists of a co-ordinator and 3.5 social workers, although during most of the fieldwork period there were only two members of staff) works closely with external professionals. Good relationships have been established, for example, with Special Schools and with the Barnardo's West Lothian Family Support Service. In some cases, a

locally-based social worker, for example, a Resource Worker for the Mentally Handicapped based in an Area team, may refer a family to the scheme and continue to carry responsibility for supporting that family throughout the match.

It has been suggested that considerable anxiety may surround the ending of matches (Oswin, 1984). Carers may become very attached to a particular child; parents may grow over-dependent on carers, who may worry about letting them down. It is possible that the informal nature of the arrangements results in a certain lack of clarity regarding at which stage and in what manner a particular link might come to an end. The Lothian Scheme has recently introduced a set of guidelines for carers, whereby they are asked to make a two-year commitment to the scheme. Individual matches are also subject to annual three-way reviews. However, these arrangements were not in operation during the fieldwork period, at which time the future of matches was considerably more open-ended.

In view of the rapid expansion of family-based respite care services throughout Britain, it may seem surprising that very little independent evaluation has taken place. Many agencies have issued short reports, often intended for internal consumption and most have produced a number of leaflets or information sheets which outline details of their scheme's operation. A major exception, however, is the Avon Family Support Service, which was recently the subject of a two-year evaluative study carried out by the University of Bristol (Robinson, 1986).

Oswin's recent study (1984) of residential short-term care facilities identifies a range of issues which require more detailed evaluation - the existence of widespread homesickness among

children, the misguided efforts of professionals to persuade parents to use services against their will and the inflexibility of many organisational procedures, which may fail to take account of families' real needs. Oswin concludes that short-term care, rather than alleviating stress, may actually exacerbate it by wrongly assuming that a child who is handicapped will be experienced as a burden by her parents and that her removal from the family for short periods will benefit all concerned. Although Oswin suggests that family-based schemes may avoid the pitfalls of residential short-term care, they form such a small part of her study that no firm conclusions can be drawn.

Indeed, a number of critical questions about family-based respite care have been raised by Campbell (1983): that it may mask a need for reception into care, discriminate against families who lack negotiating or organising skills and has no close monitoring controls. Campbell recommends that further research should examine the quality of care provided, the extent to which schemes are successful in meeting parental expectations and the reasons why some families prefer not to make use of this type of care.

Summary and Conclusions

In this chapter it has been suggested that, for the greater part of this century, children with disabilities were excluded from the general remit of childcare policy and were largely treated as part of 'the mentally handicapped population'. However, the wider movement towards community care for this client group, along with an increasing acceptance of normalisation principles, led to a more child-centred approach in both policy and practice.

Although the vast majority of children now live at home with their families, the development of community-based support services has proved a slow and problematic affair. Furthermore, certain factors within the current social and political climate were identified which have undermined the ability of both the formal and informal sectors to provide parents with a high level of sustained support. Recent research has demonstrated that, within the family, the bulk of housework and childcare tasks continues to be performed by women.

Numerous studies have indicated that the presence of a handicapped child can place considerable stress upon the family, particularly in mothers. It was suggested that family-based respite care emerged largely as a response to a growing awareness of this strain, to parents' repeated identification of respite care as a priority need and to vigorous attempts to avoid inappropriate admissions of children to institutions. The introduction of the service was also linked to related developments within the field of childcare, such as the successful adoption of children with handicaps and the emergence of specialist fostering. Although family-based respite care has developed rapidly during the past decade, individual schemes vary considerably in their methods of operation, although not in their basic objectives and philosophy. They are intended to reflect principles of normalisation and good childcare practice, to offer families flexible, informal but consistent support and to give parents a significant degree of choice and control. Finally, it was noted that, despite the increasing popularity of this service, surprisingly little evaluation, particularly of a critical and independent nature, has been carried out.

CHAPTER 2

The Research Perspective

Introduction

The purpose of social research is not only to describe social phenomena but to understand, explain and interpret them through a particular frame of reference (Bulmer, 1977). Such a frame of reference may have as its basis a 'grand theory' concerning the nature of social reality, but mainly comprises a number of complementary, smaller-scale theories, capable of addressing the specific research issues (Silverman, 1985). The purpose of this chapter, then, is to construct a theoretical framework, arising out of the aims of the study, which will inform its methodology and analysis. To do this, the main objectives of the study must first be established and then placed within the context of related research.

The Aims of the Study

Although the aims outlined in the original research proposal have been modified and developed to some extent, its overall purpose has remained unchanged: to provide a detailed study and analysis of Lothian's Share-the-Care scheme and to assess how successful the service has been in achieving its own objectives. Within this framework, six specific aims can be identified.

Firstly, the study aims to monitor and evaluate the impact and effectiveness of the Share-the-Care scheme in terms of its own principal objectives; which is: to offer support to parents by reducing stress and/or enhancing their coping abilities; to provide a beneficial experience for the children using the service and to offer some degree of choice in respite care facilities to parents of

children with severe and profound handicaps, by providing a viable alternative to institutional or residential respite provision.

Secondly, the study aims to identify the characteristics of families placed on the scheme, to examine parents' experiences of using it and their perceptions of its impact on the handicapped child.

Thirdly, it seeks to explore the reasons why some families withdraw from the scheme and why others remain on the waiting list for many months.

Fourthly, the study aims to identify the characteristics, motivations, rewards, dissatisfactions and role perceptions of carers, to assess the impact of caring on their lives and to examine their perceptions of the scheme's impact on the handicapped child.

Fifthly, by exploring in detail the preceding areas, it seeks to identify strengths and weaknesses within the operation of the scheme.

Finally, it is hoped that the study will go some way towards filling the gaps in existing knowledge about family-based respite care, thus making its findings relevant to other, similar schemes.

It had originally been planned to examine the characteristics of carers who withdrew from the scheme during the fieldwork period, but as only one did so, this aim was abandoned.

A Variety of Perspectives

The study's principal objective of evaluating Share-the-Care was thus sub-divided into a range of specific aims, approaching the scheme from a number of angles. In order to address each one effectively, it was necessary to draw upon a variety of theoretical perspectives. These were: the literature on families with

handicapped children, stress and coping theory, the literature on foster care, on parental attitudes towards sharing care and, lastly attachment and separation theory. The rest of this chapter will discuss these areas in turn. Table 2.1 indicates the relation of each theoretical perspective to the aims of the study. However, it is not intended that these should be viewed in isolation from each other, as the overall purpose of this chapter is to bring them together in order to form a single framework.

TABLE 2.1 Aims of the Study and Theoretical Perspectives

Theoretical Perspective	Corresponding Research Issue Characteristics of families
Literature on Families with Handicapped Children	Impact of Caring on Family
Stress and coping theory	Effectiveness of scheme in reducing stress Impact of scheme on families' lives Reasons for withdrawals
Literature on foster care	Characteristics of carers Impact of scheme on carers Strengths and weaknesses of scheme
Parental attitudes towards sharing care	Reasons for withdrawals Impact of scheme on families' lives
Attachment and separation theory	Impact of scheme on children

It should be noted that consideration was given, during the initial stages of research, to exploring the concept of altruism, since it was speculated that this might be a significant motivating

factor among carers. Early indications arising from fieldwork strongly suggested otherwise, however, and a decision was taken against pursuing this line of enquiry.

Families with Handicapped Children

Several studies have demonstrated a link between the incidence of family stress and the experience of caring for a dependant relative, be it a disabled spouse or dementing elderly parent (EOC, 1982; Briggs and Oliver, 1985; Wright, 1983). Similarly, high levels of stress have been found among parents caring for a handicapped child at home (although research has focused primarily on mothers). In a number of cases, these findings have been obtained by means of the Maternal Malaise Inventory (Rutter et al. 1970), a 24-item fixed-choice scale designed to determine the existence or absence of certain physical ailments and emotional responses generally associated with stress. Pahl and Quine (1985), for example, used the Inventory in a study of 200 families with severely mentally handicapped children, living in south-east England. They report a mean score above the normal range, but add that variations around this figure were 'very great'. Bradshaw and Lawton (1978) found high levels of stress among a larger sample, while Chetwynd (1985), examining 91 mothers of children attending special schools in New Zealand, report significantly higher levels of stress among this sample than in mothers of non-handicapped children.

The Malaise Inventory, however, has a number of shortcomings which will be discussed in greater detail in the following chapter. For the moment, it may be noted that this instrument makes no attempt at causal analysis, fails to address the complex, cyclical

nature of stress, lacks a weighting system and allows for only affirmative or negative responses, which may reduce its validity. Indeed, other studies using the Inventory have produced different results. Burden (1980) found considerable variation among his sample of 25 mothers, tested before and after two years of home visiting by social service personnel. Wishart, Bidder and Gray (1981), comparing 47 parents of developmentally delayed children with a control group of 31 parents of non-handicapped children, found very little difference in the scores obtained from the two groups. Some differences in self-perception, however, were noted.

A significant weakness common to all these studies, which may also contribute to the variation in their findings, is the failure to develop a conceptual framework. 'Stress' is only defined in operational terms; for example, Bradshaw and Lawton describe it as 'emotional disturbance', while the observation that vulnerability to stress is likely to be a multi-faceted phenomenon is presented more by way of conclusion than as a theoretical starting-point (Burden, (1980).

Those studies which employ standardised testing procedures generally do so as a supplement to more qualitative methods, while others have relied solely on the use of interviews or questionnaires. These have sought to examine the association between stress and caring by exploring the ways in which stress is manifest within the family; this is generally referred to as 'the effects of caring' (Carr, 1975; Burden, 1980; Hunter, 1980; McAndrew, 1976). Particular attention has been paid to the marital relationship, the welfare of siblings, the emotional and psychological well-being of mothers and to families' ability to

function adequately on a social level. The emphasis, then, is on intra-familial aspects. Again, results have often proved inconsistent and conflicting. To illustrate this point, it may be worth examining the findings about intra-familial relationships.

A number of studies have suggested that caring for a handicapped child can have an adverse effect on the marital relationship. McCormack (1978), herself a parent, interviewed over 50 families throughout Britain. She reports a catalogue of severe marital problems, including disagreements over the child's upbringing, reduced spontaneity, unsatisfactory sexual relationships and withdrawal on the part of husbands. Chetwynd (1985) reports a high incidence of marital breakdown, 24% of mothers living without a permanent partner, as opposed to 12.9% in comparable samples of mothers of non-handicapped children. Lonsdale (1978) who interviewed 60 parents of varying social backgrounds drawn from one English city, records that 55% felt their marriage had deteriorated as a result of caring, 28% felt it was unaffected, while 17% had experienced an improvement. Other studies have produced a more balanced picture. Waisbren (1980) compared 30 parents of developmentally delayed children aged less than one and a half years with 30 parents of non-handicapped children of the same age. Both groups reported changes in the nature of their relationship since the child's birth:

more intense feelings of intimacy as well as more tensions,
(p.348)

but those with handicapped children reported no greater strain. It could be argued, however, that differences would more likely emerge as the children grew older. Kendall (1982) reports that a majority of parents believed the child's presence had no negative effects on their marriage, although at 18, his sample is small, while almost a third of McAndrew's respondents ($N = 116$) report that the child's presence had strengthened their relationships. It was suggested many years ago that this interaction is related to levels of integration prior to the child's birth, which may then strengthen a good marriage or undermine a poor one (Farber, 1959).

Similar variation emerges from the findings about the disabled child's siblings. McCormack (1978) reports that siblings suffer in a variety of ways: they may be taunted by other children, avoid bringing their friends home, receive insufficient parental attention or become the subject of unrealistically high parental expectations. Kew (1975) and Brorone (1983) take a corresponding view. On the other hand, Lloyd-Bostock (1976), who surveyed 97 parents by means of a postal questionnaire, reports that, in a majority of cases, the child's presence was thought to have had positive effects on his siblings, although some parents believed their other children had been forced to assume unfair responsibilities at an early age. Elsewhere, 15% of 233 siblings are reported to have 'some emotional problems' (McAndrew, 1976) while other investigations have found a 9% level of 'behaviour disorder' (Lonsdale, 1978). Carr (1975) interviewed the mothers of 54 Down's Syndrome children, aged 4 or under, matched to a control group of mothers of non-handicapped children. Over two-thirds of the siblings in each group were described as 'easy children who gave no real trouble'. While the

Down's mothers did express some concerns about potentially negative effects of the child's presence on his siblings, few had actually emerged, although some siblings were thought to be jealous of the handicapped child. Surveying the literature in this field, Simeonsson and McHale (1981) suggest that research has wrongly focused on the handicapped child's supposed pathology, assuming that negative effects on siblings are likely to ensue. Instead, they argue, attention should be paid not only to the potentially therapeutic aspects of the relationships, but also to the complex nature of family functioning.

Indeed, even this short appraisal has indicated that some studies have tended to separate out individual aspects of the family structure and treat these in isolation from other aspects with which, in reality, they are constantly interacting (Bulbolz and Whiren, 1984). Having identified the existence of 'stress' in certain areas, a link has been made between this and the presence of the handicapped child, by means of a cause and effect analysis of stress which does not fully take into account the interactive dimensions of the family unit. Again, this weakness in the literature appears to be related to the absence of a well-developed theoretical framework which would place such research within the context of normative family functioning.

Research which concentrates on the 'effects' of caring has also been criticised for its failure to explore possible solutions (Cunningham and Byrne, 1985). On the other hand, many studies have, in addition or as an alternative, sought to identify which particular aspects of caring give rise to stress. Since this approach may yield information valuable in the planning of future

services, it seems a useful one. Attention has been paid, for example, to those characteristics of the child which parents find most demanding. Behavioural problems, nocturnal disturbance, multiple handicaps and poor health in the child have been identified as factors 'causing most stress to mothers' (Pahl and Quine, 1985). Feeding difficulties and a low level of self-help skills are said to be a source of 'major problems' (Carr, 1975). Other causes of stress associated with the child are the prospect of prolonged dependency and the need for constant supervision (Glendinning, 1983) and the child's age and severity of disability (Wilkin, 1979). However, other studies have concluded that there is no direct link between characteristics of the child and the degree of stress experienced by parents (Bradshaw and Lawton, 1978; Kendall, 1982).

The role of factors external to the family has also been examined. Pahl and Quine (1985) conclude that 'social adversity' is a major cause of stress, while several studies have referred to 'social isolation', particularly in mothers (McCormack, 1978; Hewett, 1970; Kendall, 1982). Evidence of financial hardship has been found among families with severely disabled children, along with a lower rate of income compared with that of a matched control group without handicapped children (Baldwin, Godfrey and Staden, 1983).

Other studies have concentrated on the physical demands of caring, the unremitting nature of the task, termed by Bayley (1973) 'the daily grind', and the need for practical assistance. This body of research has been identified by Wilkin (1979) as using a 'normal family model' since it emphasises the similarity of its respondents to the parents of non-handicapped children, arguing that the

provision of adequate support services would allow families with disabled members to function at a similar level, both socially and emotionally, to any other. Hewett (1970) compares the results of interviews conducted with 180 mothers of handicapped children in Nottingham with those gained by Newson and Newson (1968) about urban four year olds. Many areas of similarity emerge between the two groups, the principal difference being described by Hewett as the greater need of her respondents for support services. She reports that her sample raised their children according to whatever parenting norms they ascribed to prior to the child's birth and did not deviate from these significantly because of the child's handicap.

The picture which emerges from this and other studies regarding parents' view of service provision and the level of unmet need, is a disturbing one (Glendinning, 1983; Lonsdale, 1978; Hunter, 1980). Social work intervention is characterised in terms of crisis intervention, rather than the provision of ongoing support capable of meeting practical everyday needs (Wilkin, 1979). The main conclusion reached by this body of research, as Lloyd-Bostock (1976) makes explicit, is that families face greater difficulty in obtaining constructive assistance from services than they do as a direct result of the presence of handicap.

Numerous recommendations are made for change and improvement. As general principles, it is proposed that service delivery should be regular, reliable and locally based (Bayley, 1973), accessible and flexible (Lonsdale, 1978), and punctual (Hunter, 1980). In more practical terms, many specific types of service are recommended for development, respite care being the most popular choice. The need

ranges from day care, after school provision and child-minding services (Younghusband, 1970), to regular short breaks away from home (Hunter, 1980; Lloyd-Bostock, 1976; Wilkin, 1979; McAndrew, 1976). These findings have been important in setting the tone and direction of current services.

Attention has also been paid within the 'normal family model' to the role of informal support networks. The division of responsibilities within the family for physical care is measured against the practical contribution of extended family, friends and neighbours. While concluding that such support is currently at a low level (Wilkin, 1979; Kendall, 1982), the potential of stronger support networks to reduce stress is emphasised. Such conclusions have been challenged by Bradshaw and Lawton (1978), using the Malaise Inventory, who assert that the input of goods, services, cash or indeed any resource would fail to reduce stress significantly.

However, the 'normal family model' does have certain limitations. Firstly, in its concentration on practical demands and material needs, it pays insufficient attention to the role of emotional and psychological factors which, it may be argued, also contribute to the aetiology, manifestation and relief of stress. Secondly, by tending to conclude that every family's experience of handicap is unique (Kendall, 1982; Hewett, 1970), it greatly reduces the scope for generalisability of its findings (Cunningham and Byrne, 1985). Thirdly, it is, again, largely atheoretical. Indeed, its status as a 'model' may be challenged, since that term denotes:

... tentative theoretical structures designed, (1) to integrate subsets of existent data and, (2) to predict new relationships within a domain (Garmezy, 1982, p.79)

by generating testable hypotheses.

Hunter (1980) refers to early intervention theory and the significance of life cycle stages in the incidence of stress but does not develop these themes. Considerable weight is given to the validity of parents' subjective opinions, but the function of perceptions as a potential coping resource is not examined. Both Bayley (1973) and Hunter (1980) use the concept 'structure for coping' to indicate the daily management routines which parents evolve in order to master 'the daily grind' and make the important point that, in order to be acceptable, service provision must fit into these structures, rather than expect the latter to fit into them. The role of informal support in reducing stress is examined, but measured largely in terms of practical tasks, rather than according to the quality or nature of a family's network. While these themes remain largely undeveloped in the research mentioned above, they all have an important contribution to make in the development of a conceptual framework appropriate to the study of caring, stress and support, as I shall shortly discuss in more detail.

In conclusion, it is clear from the literature that the presence of a handicapped child is often associated with the incidence of considerable family stress. However, the exact nature of this interaction and the reasons why families should vary considerably in their experience of such stress are less clear. The inconsistent and often conflicting findings arising from this field of research may be partly related to its largely atheoretical basis.



'Stress' is seldom defined in conceptual terms; a somewhat simplistic cause and effect approach to analysis is common, confused at times by a failure to distinguish between the aetiology and manifestation of stress. Similarly, insufficient attention has been paid to the complex, interactive nature of normative family functioning. The lack of a well-developed theoretical framework also reduces the scope for generalisability of the findings. On the other hand, certain important themes emerge. These are: the validity of parental perceptions, the potential of external supports to reduce stress and the concept of 'a structure for coping'.

In order to explore these concepts further, I shall now examine some theoretical insights from the literature on family stress and coping and their relevance to the study of families with handicapped children.

Family Stress and Coping Theory

For many years, research in this field was dominated at a theoretical level by Hill's ABCX model of family crisis (1949), according to which A (the stressor event) - interacting with B (the family's crisis-meeting resources) - interacting with C (the definition the family makes of the event) - produce X (the crisis). However, some important modifications have been made to the model since its inception. The term 'stressor' has been defined in a number of ways but, for the purpose of the present study, the following conceptualisation will be useful. A 'stressor' is:

... a life event or transition impacting upon the family unit which produces, or has the potential of producing, change in the family social system. This change may be in various areas of family life, such as its boundaries, goals, patterns of interaction, roles or values.

(McCubbin and Patterson, 1983, p.8)

In this sense, the presence of a handicapped child may be said to act as a stressor within the family, since it may cause parents to revise their 'normal' expectations of a child (Longo and Bond, 1984), alter the nature of a family's transactions with the wider social environment (Crnic, Friedrich and Greenberg, 1983) or, by requiring each parent to specialise in a distinct sphere of activity, may effect changes within roles and boundaries (Kazak and Marvin, 1984). Burr (1973), reworking the ABCX model, introduced, alongside the 'stressor', the concept of its 'associated hardships', to denote those demands made upon the family as a direct result of the stressor's presence. It is not clear that the changes referred to above necessarily involve any element of 'hardship' as such. However, in terms of the substantive findings of research discussed in previous pages, 'associated hardships' could indicate a need for constant supervision, a high level of physical care, increased financial demands and so on. It has been noted that, while one stressor may be insufficient to produce a crisis, the presence of multiple stressors, accumulating over time, may do so. This process, in which the final precipitating factor may be a relatively minor one, has been termed the 'pile-up' effect (Mederer and Hill, 1983). Thus, a family coping adequately with the demands of caring for a handicapped child, may face a crisis when an accustomed source of support, be it holiday playscheme or regular childminder, is withdrawn. Similarly, Rutter (1978) has shown that while most children can cope well with 'single acute stressors', 'recurring multiple stress' is more likely to be damaging.

The 'B' factor, families' crisis-meeting resources, was originally conceived in terms of internal, or intra-familial

variables, such as levels of integration and adaptability, the mutual identification of shared goals and co-ordinated attempts to achieve these. The ABCX formulation, however, implies that such resources would only be brought into play in order to reduce or mitigate the effect of an approaching crisis, rather than having an ongoing function aimed at the maintenance of effective coping behaviour, a point to which I shall return later. The family's 'definition of the event' is identified as a separate item in the equation, underlining the crucial significance of subjective perceptions, which may differ from cultural definitions, in determining a stressor's impact on the individual family (Folkman, Schaefer and Lazarus, 1979). Finally, it may be noted that this model implies that some form of crisis, albeit of varying degrees, is an inevitable outcome of the stressor event, a 'crisis' being:

... a continuous variable denoting the amount of disruptiveness, disorganisation or incapacitatedness in the family social system.
(McCubbin and Patterson, 1983, p.10)

However, Hill (1949) also allowed for the possibility of 'roller-coaster adjustment', whereby a family might progress from initial disorganisation at the time of crisis (such as the birth or diagnosis of a handicapped child) through gradual recovery to eventual reorganisation. This formulation corresponds well to the view that the long-term presence of the child within the family does not necessarily constitute an ongoing crisis (Wilkin, 1979; Longo and Bond, 1984), although it may continue to act as a stressor.

Following the Vietnam war, research into families' response to enforced separation from their menfolk confirmed that crisis was not an inevitable nor irreversible outcome and that families were able to make adjustments over time. Thus Burr (1973) incorporated into

the ABCX model the concepts of vulnerability and regenerative power. Again, this allows for the finding that families react in differing ways to the presence of a handicapped child, many being able to overcome their initial shock and successfully adapt to the demands placed upon them (Longo and Bond, 1984; Simeonsson and Simeonsson, 1981). Before going on to discuss the coping process, however, it is necessary to examine the concept of 'family stress' as opposed to 'stressor' or 'crisis'.

The term 'stress' has proved notoriously difficult to define (Rutter, 1981). Lazarus (1966) distinguished between three levels of analysis; the physiological, psychological and sociological. The first is concerned with the neurological functioning of organisms, arising from Selye's work on biological arousal (1950, 1965). At the psychological level, Lazarus examines the cognitive process which measures the 'goodness of fit' between the demands imposed by a stressor and the individual's capacity to deal with them, the resulting shortfall being identified as 'stress'. Again, this formulation relies heavily on the role of subjective perceptions and the meanings ascribed to events by the individual. It may be less easy to arrive at an adequate sociological definition of stress (Klein, 1983) and certainly that offered by McCubbin and Patterson (1983) owes much to Lazarus:

... a state arising from an actual or perceived demand-capability imbalance in the family's functioning and which is characterised by a multi-dimensional demand for adjustment or adaptive behaviour.
(p.9)

It is important to emphasise that stress itself is not necessarily a destructive nor 'unpleasant' phenomenon. Rather, it can act as a positive force, by motivating families to bring about constructive

change, whereby their various functions are more efficiently performed. This process can be related to a central tenet within family systems theory, namely, that a system has a natural propensity to evolve towards positive growth and change (Walrond-Skynner, 1976). 'Distress', on the other hand, arises when the family's subjective experience becomes unpleasant, negative or disorganised (McCubbin and Patterson, 1983). It may be inferred from the above that families with handicapped children will vary in the degree of stress they experience, those facing low-level stress being able to function effectively, while those under higher levels are more likely to become 'distressed'.

However, stress does not arise only in response to unusual, 'one-off' events, nor to situations marked by long-term pressures, but also occurs within the course of normative family functioning and development. While it will not be necessary to explore this area in detail here, certain basic points should be established. Firstly, both individual members and the family as a whole undergo a degree of stress at crucial stages of the life-cycle (Rapoport, Rapoport and Strelitz, 1977). Indeed, according to Erikson's theory of eight psychosocial stages (1963), the negotiation of important developmental tasks is almost a continuous process. Although transition periods are stressful, the fact that they can be anticipated and are universally experienced makes them more manageable (McCubbin et al, 1980). Failure to make successful transitions, however, can undermine family stability and growth (Turnbull et al, 1984). Clearly, this may have serious implications for families with handicapped children, since the latter may fail to achieve developmental milestones and certain phases of parenting may

distress
stress

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be prolonged or delayed.

It has also been noted that families face a certain amount of stress as they attempt to fulfil a variety of functions. These have been identified as economic, physical, rest and recuperation, socialisation, ideology, self-definition, affectional, guidance, educational and vocational (Turnbull et al. 1984). Each individual has specific needs in these areas and the family unit attempts to manage resources in such a way as to ensure they are met. Pratt (1976) developed the concept of 'the energised family' as one which achieves a healthy balance between individual and group interests. Again, there may be added challenges here for families with handicapped children, who may have special needs in these areas but are less able to contribute towards meeting them. Turnbull et al comment:

It is strikingly clear that a challenge for families is the development of sufficient time and stress management skills so they can execute these functions in an efficient, systematic and relaxed manner.
(p.134)

The development of 'stress management skills' is therefore an important task for all families, irrespective of handicap. Thus, families are not simply passive reactors to stress, but actively seek to develop effective coping strategies (Lazarus, 1966; Folkman, Schaefer and Lazarus, 1979; Klein, 1983). The successful achievement of such behaviour has been described as:

... approaching life by creative problem-solving and by efforts to develop mastery and control over events, rather than by application of standardised solutions and passive submission to events.
(Pratt, 1976, p.109)

However, insufficient attention has been paid, at both the clinical and theoretical level, to families who function well (Longo and Bond, 1984), and few conceptual frameworks are available for developing knowledge in this area. Building on the ABCX model, however, attempts have been made to identify the coping resources which may be available to families. Folkman, Schaefer and Lazarus (1979) have outlined the following categories: health/energy/morale, problem-solving skills, social networks, utilitarian resources, and general and specific beliefs. It was noted earlier that the literature sometimes examines these areas in terms of the deleterious effects caused by the demands of the handicapped child. Here, the interaction would be approached from a different angle, to determine whether good health, for example, could be mobilised as a coping resource. For the purpose of the present study, the roles of social networks and utilitarian resources are particularly relevant.

McCubbin (1979) pointed out that studies of adaptation to stress focused mainly on intrafamilial mechanisms, neglecting the significance of transactions with the community. Schilling, Gilchrist and Schinke (1984) present social supports and internal coping mechanisms as complementary parts of a whole strategy, but comment that the two concepts remain largely undeveloped, lacking a unified knowledge base. The importance of social integration for psychological well-being and the capacity of external supports to enhance self-esteem by increasing coping efforts, was established by Cobb (1976). In relation to families with handicapped children, the social network operates at three levels; individual family and household members, extended family, friends and neighbours and, thirdly, the formal services (Schilling, Gilchrist and Schinke,

1984). Clearly, then, a family-based respite care scheme can be conceptualised as a social support.

Bulbolz and Whiren (1984) have explored some aspects of the relationship between 'internal' and 'external' coping resources, in their 'ecosystem' model of the family, which draws on a number of theoretical insights examined in previous pages. The demands of one individual within the family may require extra energy input from other members, engendering stress which can act as a motivating force for positive change. In order to meet this challenge, the family will utilise certain internal resources but, since in any case it is constantly interacting with the wider social environment, may also call on external resources for support. These activities require the expenditure of human energy, supplies of which are limited. Excessive demands create 'energy sinks', when adaptive and creative behaviour may no longer be maintained. Those under most stress may therefore be least able to secure external resources. On the other hand, the successful procurement of supportive inputs may be the deciding factor which enables families to function effectively, albeit with a high energy expenditure. Clearly, this model has important implications for the evaluation of a family support system, such as Share-the-Care, since it implies, among other things, that services should be designed in such a way as to maximise the benefits and reduce the costs to all family members. The more 'distressed' parents, however, may experience difficulty in utilising the resource.

Venters (1981) in a study of 100 parents of cystic fibrosis sufferers, found a significant association between the 'long-term adequacy of family functioning' and variation in styles of coping.

The two strategies which emerged as particularly effective were, firstly, the ability 'to endow the illness with meaning' (for example, by perceiving it within the context of religious beliefs) and, secondly, 'sharing the burdens of the illness', both within and outside the family. Not only did this strategy secure invaluable practical assistance with the physical tasks of caring, it also attracted emotional support which sustained intrafamilial morale. Venters describes this process, which involves a complex transaction between internal and external mileaux, as:

... maintaining an equilibrium between family
loyalty and social participation which results in
social support.
(p.295)

He also emphasises the importance of families perceiving as helpful those supports which they have, corresponding to Lazarus' concept of 'goodness of fit'.

Supporting evidence is available from a study by German and Maisto (1982) who interviewed 112 families with handicapped children in Carolina. It emerged that those who saw themselves as facing relatively few stressors, and who received a higher level of support, both at the formal and informal levels, were least likely to seek residential care for their children.

However, other studies demonstrate that the relationship between stress and social 'support' networks is a complex one, and that the latter does not necessarily act as a buffer between the family and stress. Waisbren (1980) suggests that while the availability of social supports may enable parents to relate well to their handicapped child, there may be a 'trade-off' in terms of internalised strain, expressed in physical symptoms or marital

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problems. Kazak and Marvin (1984) argue that network size is unrelated to the incidence of stress, but effectiveness may depend on its structure and composition: a small, highly interconnected and family dominated network may create stress, by forming a relatively closed system and blocking access to wider supports. A highly developed friendship network may be more efficient in reducing stress. This suggests that a family-based respite care scheme, in which parents and respite carers are encouraged to develop friendly relationships, may be an effective vehicle for reducing stress, but that the quality of relationships within individual matches will be significant. Granovetter (1975) and Hammer (1983) go further, emphasising the benefits of weak ties and multiple casual contacts. Through these, the individual has wider access to opportunities within the community, is more likely to be well-integrated and to enjoy good health. It has also been noted that 'faulty' coping mechanisms may only increase levels of stress experienced by the family (Rutter, 1981).

Cunningham and Byrne (1985) have brought together many of the ideas discussed in this section, and other related concepts, within the framework of a 'transactional model'. This model was developed by Sameroff, Seifer and Zax (1982), examining the aetiology of schizophrenia. Finding neither biological nor environmental explanations to be adequate in themselves, the authors argue that attention should be paid to the 'dynamic transactions' which take place between 'internal' and 'external' spheres. The model conceives of the family as an interactive system within a wider social context. While acknowledging the existence of stress, it also seeks to identify the competence of families who have handicapped

children, the differences between them and their similarities to those with non-handicapped children. It has already been noted that Share-the-Care is intended to reflect principles of good childcare practice and normalisation. It would therefore seem appropriate, while evaluating it, to use a framework which emphasises that these children share the same basic emotional and psychological needs as any others. Cunningham and Byrne also call for an examination of parents' coping strategies and the resources needed to sustain them. Again, this seems particularly appropriate to a sample of families which has applied to use Share-the-Care, if their attempt to secure the service is conceptualised as an active coping strategy, and the scheme itself, being a form of social support, is seen as an external resource. Finally, Cunningham and Byrne point to the need to test the effectiveness of the various resources available to parents. This again calls for the evaluation of services such as Share-the-Care.

In conclusion, it has been suggested that all families experience a certain amount of stress as they attempt to fulfil their various functions and negotiate a series of life-cycle stages. The presence of a child with disabilities acts as an additional stressor by imposing certain demands which may produce change at various levels of the family system. However, families are not simply passive reactors to stress. They actively seek to manage it by mobilising internal resources and/or by seeking external supports. Share-the-Care may be seen as such a support. The nature of subjective perceptions is also an important determinant of a stressor's impact. It was noted, then, that families vary not only in their levels of stress but also in their styles of coping.

However, while several studies have suggested that the provision of external support is an effective aid to coping, these cannot be procured without a certain amount of energy expenditure. Families under most stress may therefore be least able to secure these resources. Finally, it was noted that stress can be created or exacerbated through the use of faulty coping mechanisms.

Insights from Foster Care

It has already been noted that, while family-based respite care is a relatively recent development, complementary and substitute care of children has a long history. Given the paucity of detailed empirical research on respite care, it would seem important to make use of some concepts drawn from the literature on fostering. Although significant differences exist between the two, respite care has been conceptualised as a type of fostering (Shaw and Hipgrave, 1983; Oswin, 1984) and, as discussed in the preceding chapter, its origins owe much to that tradition. Two aspects of the literature may be particularly relevant here; firstly, the orientation of foster parents, secondly, a number of practice issues which have recently been highlighted.

Fanshel (1966) examined the characteristics and role perceptions of 101 foster parents in the United States. He reports that most had 'a simple lifestyle' and a 'non-reflective orientation to the world about them'. They tended to come from working-class backgrounds, to be 'home-centred' and 'child-oriented'. The majority were not interested in attending preparation nor training meetings and, clearly, did not view themselves as engaged in a professional task. Rather, the emphasis was on the child becoming part of the family - and remaining as such. These foster parents perceived the possession

of 'ordinary' parenting skills as the main qualification required for their task. Fanshel identified their principal rewards as 'private pleasures' (arising from close attachments to infants) and 'social gratifications' (among those caring for older children, who believed they were performing a useful service for the community). In line with foster parents' own perceptions of their role, it was considered unthinkable at that time to offer financial incentives or rewards beyond reimbursing the expense of providing for the child. Their orientation towards fostering might be described as 'traditional'. It is worth noting that the idea of caring for children with mental handicaps was not popular with this sample. 23% were not prepared to consider the possibility, while 62% imagined the problems posed by such children would be considerable.

Four years later, a similar profile emerged of 185 British foster parents (George, 1970). 60% perceived themselves as akin to natural parents, and 30% to adoptive parents. Child care officers were viewed more as family friends than as representatives of a formal agency whose task it was to restore children to their natural parents. As a result, areas of difficulty within the placement were unlikely to be reported. About two-thirds were willing to allow natural parents to visit, but only if they complied with certain conditions. Most foster parents were not in favour of receiving a salary nor attending training and discussion groups. George concludes, however, by arguing for the 'professionalisation' of foster parents. Besides allowing Departments to make greater demands of them, it would also underline the fact that the objective of fostering was to return the child to his own parents wherever possible, unless the placement was clearly planned to be long-term.

A recent study by Macaskill (1985) of 20 adoptive parents of mentally handicapped children again reveals a predominantly 'traditional' orientation, not surprisingly, given the permanent nature of these arrangements. Motivating factors among this sample included child-centredness, previous positive experience of people with disabilities and an experience of loss. Because they wished to avoid further loss, these adopters were keen to take on a handicapped child, who was seen as unlikely ever to be 'removed'. Remarkably few difficulties were reported, the main problems apparently arising from the obstructive attitudes of social workers, who tended to hold negative views about the wisdom of placing handicapped children for adoption. It may be speculated, however, that the 'traditional' orientation of these adopters would discourage them from reporting any difficulties even to a sympathetic researcher!

The specialist forms of fostering which have emerged in recent years, such as 'treatment', 'bridge' and 'assessment' fostering, incorporate many of the features recommended by George, and thus provide a contrast to the 'traditional' approach. As discussed earlier, these foster parents receive a higher rate of remuneration, more intensive training and support in exchange for performing a wider range of tasks requiring a variety of skills, including working closely with natural parents in rehabilitating the child. These foster parents seek fewer 'personal gratifications' than do their traditional counterparts, tending to perceive unresponsive behaviour, for example, as an aspect of their job which they are expected - and paid - to deal with in a professional manner (Shaw and Hipgrave, 1983).

This type of foster parent has been described by Wolfarth et al (1985), evaluating a Barnardo's fostering scheme for mentally handicapped children, as 'para-professionals and of equal status with other members of staff', having also a therapeutic role. Areas of motivation in this sample include an interest in handicap, a fondness for children and previous experience of fostering, coupled with the desire to utilise acquired skills. The wish to perform a socially useful activity was equally important. These foster parents are described as being enthusiastic about, and committed to, preparatory training. The authors also emphasise the need for a high level of on-going support, including the provision of an emergency call-out service and the availability of respite care.

Thus, it is possible to distinguish between 'traditional' and 'professional' orientations to fostering. Holman (1980) draws a similar distinction between 'exclusive' and 'inclusive' forms of fostering. By the former, he means a type of care which

attempts to contain the foster child within the foster family while excluding other connections.
(p.75)

Such foster parents are anxious to avoid any factors which might threaten or disrupt their ability to 'possess' the child. 'Inclusive' fostering, on the other hand,

... is based on a readiness to draw the various components into the fostering situation. The foster parents can offer love without having to regard themselves as the real parents.
(p.77)

These concepts can also be related to parental attitudes towards sharing care, as will be discussed shortly.

In seeking to relate these findings to a family-based respite care scheme, two opposing possibilities emerge. On the one hand, the service provides complementary care, intended to act as an ongoing support to parents who are not necessarily encountering difficulties in caring. Thus, there is no question of respite carers providing long-term nor substitute care. The aim is to enhance the coping abilities of natural parents, with whom respite carers are encouraged to develop friendly relationships. Again, there is a specialist element involved, since the children all have disabilities. These points might suggest that carers would have a 'professional' orientation. On the other hand, while the care is short-term, it is provided by the same carers to the individual child, on a one-to-one basis, possibly for several years. Indeed, it might be speculated that successful placements would depend on the development of close, affectionate relationships whereby the child becomes 'part of the family'. Again, the Lothian Scheme does not employ respite carers as paid workers, but as semi-volunteers, who are not compelled to attend preparation sessions nor support groups. These factors argue for a more 'traditional' orientation. As noted earlier, it might be speculated that carers are altruistically motivated. However, Blau (1967) suggests that while 'an apparent altruism pervades social life' (p.17), in reality people gain valuable social rewards and approval from helping others, while also reaping intrinsic psychological rewards from genuine personal attachments, resulting in a process of reverse secondary re-inforcement. It will be important to bear in mind these insights from the literature while exploring the characteristics of carers and the resulting implications for other aspects of the scheme.

A number of additional issues can be identified from this field of research which may be relevant to family-based respite care. Jenkins and Norman (1972) drew attention to a widespread failure on the part of social workers to recognise and address the needs of natural parents who were found to suffer 'filial deprivation' when their children were placed with foster parents, a point which will be elaborated later. Sinanoglu and Maluccio (1981) argue that the whole family should be seen as 'the client', a perspective which would be advocated also by the transactional model and is of particular relevance to a family support service. Aldgate (1980) stressed the importance of parents having as much sense of control as possible over the placement, both by thorough pre-placement preparation and by the provision of social work support appropriate to their individual needs.

Several recent commentators have called for greater preparation and support not only of parents but also of children and foster parents (Berridge and Cleaver, 1986), since this is associated with a decreased risk of breakdown (Cautley, 1980). Earlier studies of child-minding made a similar point (Mayall and Petrie, 1977; Bryant, Harris and Newton, 1980). Triseliotis (1988a) has emphasised the need for clarity in the respective roles and responsibilities of foster parents, natural parents and social workers, and the importance of directing individual foster parents towards the type of caring most suited to the nature of their motivation. Since present-day fostering encompasses a number of differing care situations with varying objectives, it is also vital to match the expectations of the carers to the needs of the child. Triseliotis warns that the characteristics and attributes of all parties concerned - child,

parents, foster-carers and social workers - contribute to the success or failure of placements. Berridge and Cleaver (1986) stress the benefits of maintaining a child in her own locality and of continuity in schooling. Finally, Shaw and Hipgrave (1983) have underlined the complexity of:

... the apparently attractive concept of 'shared care' for children [which] touches upon primitive feelings of which none of the parties concerned is more than dimly aware.
(p.60)

e.g.
X

To summarise briefly, two distinctive types of foster care have been identified from the literature, the 'traditional' and 'professional'. It was speculated that elements of each may attach to respite carers. However, as respite care differs from fostering in some significant aspects, it is also possible that another, different, orientation pertains here. Secondly, certain practice issues were noted from recent research: the need to see the whole family as client, to encourage parents to take an appropriate level of control over placements, the importance of thorough preparation and support for all concerned and for clarity in the roles and responsibilities of each. Finally, reference was made to the emotional and psychological complexities inherent in the shared care situation. It is now time to examine that issue from the parents' viewpoint.

Parental Attitudes Toward Shared Care

In this section, I shall examine some concepts arising from the somewhat limited literature on parental attitudes towards shared care, in both formal and informal settings. In doing so, I am

bearing in mind that the transactional model focuses on areas of similarity between parents of handicapped and non-handicapped children. A major theme to emerge from this body of research is the prevalence of ambivalent feelings and reservations among parents.

In some cases, this has been related to the structure of the service or the nature of the shared care situation. The main reason for disquiet among mothers using child-minders, for example, is said to be the poor quality of care on offer (Mayall and Petrie, 1977; Bryant, Harris and Newton, 1980). The mothers interviewed in these studies perceived themselves as having little or no control over events in the minders' home: some believed the child was receiving inadequate stimulation or were uncertain if he was happy at the minders, yet they experienced difficulty in raising such issues. Bryant et al relate this fact to certain ambiguities inherent in the mother/minder relationship.

The nature of service delivery was also identified by Oswin (1984) as intensifying parents' anxieties about using short-term care facilities. Inflexible, bureaucratic procedures, coupled with the failure of many social workers to appreciate parents' 'natural' worries about separation from their children, prevented many respondents from relaxing and enjoying the break. Again, some parents tended to avoid raising these issues with social workers, apparently for fear of losing the service altogether.

Any element of compulsion, then, may increase parents' ambivalence about sharing care. Those who already face pressures in their lives may perceive the removal of their children into foster care as evidence of their own shortcomings. Thus, McAdams (1972) refers to 'inevitable feelings of jealousy and competition' between

natural and foster parents, a perception which corresponds to Fanshel's findings about the attitudes of 'traditional' foster parents. Jenkins and Norman (1972) developed the concept of 'filial deprivation' to describe parents' feelings of loss, sadness and anxiety when their children were fostered. Some parents felt guilty and ashamed: this was associated with behavioural difficulties in the child. Similarly, Hill (1984), studying shared care of pre-school children in both formal and informal settings, found that where care was perceived as burdensome, because a child was considered 'difficult' or where undue physical demands were involved, parental concern about imposing on others was increased.

However, the most significant factor determining parental attitudes towards sharing care, at least in those situations which involve an element of choice, is likely to be a mixture of cultural values and personal beliefs surrounding the concept of parental responsibility. Backett (1982), in a study of the development and negotiation of parental behaviour among middle-class parents of non-handicapped children, refers to a 'taken for granted' belief that a mother should always be available to her child, coupled with a perception of the latter as likely to be upset if left alone with unfamiliar people. In some cases this was linked to values of self-sufficiency and the 'privacy' of family life which, it was suggested earlier, have been reaffirmed by the non-interventionist policies of the present administration. Backett comments:

About a third of the respondents actually indicated that to resort to outside advice was somehow an admission of failure to cope with something they should have been able to resolve themselves.

(p.101)

It is worth noting that a number of reports on family-based respite care schemes have noted parents' difficulties in adapting to the shared care situation, particularly in the initial stages of contact. It has been suggested that worries about appearing to 'abandon' their parental responsibilities may be a contributory factor (Bird, 1982; Caudrey, 1984; Banks, Grizzel and Strettle, 1984). On the other hand, Robinson (1987) in a much more detailed and comprehensive evaluation of the Avon Family Support Service, encountered few such reservations. Again this suggests that a number of interacting factors determine the nature of parental attitudes, including the nature of service delivery. In Avon, respite carers act as professional workers.

An important distinction has been drawn by Hill (1984) adapting the 'inclusive' and 'exclusive' concepts first used by Holman (1980) in relation to foster care. Hill now relates these terms to parental attitudes towards sharing care. Those who exhibit an 'exclusive' orientation believe it is their duty to personally provide the bulk or even the totality of childcare, while those with more 'inclusive' attitudes perceive their responsibility to lie in the organisation or provision of childcare, thus legitimising the use of substitute carers to a greater or lesser extent. Hill also identifies two corresponding perceptions of what is most beneficial to the child, which he calls the 'attachment' and 'social exposure' models. Thus, while some parents believe the young child needs a secure, protective relationship with his parents and may not yet be ready to cope with extended separations, others perceive him as likely to benefit from establishing a small measure of independence and from the stimulation of mixing with different people.

Throughout his sample, which was drawn from two 'middle-class' and two 'working-class' districts of Edinburgh, Hill found: '... a low level of care which was not characterised by some form of exchange'. However, some differences did emerge between the class divide. Parents who had manual occupations tended to share care less frequently, preferring to use only their close relatives as childminders. They were particularly reluctant to leave their children with 'strangers', a term used at times to denote anyone outside the immediate extended family (i.e. their own parents and siblings). Those with professional backgrounds, on the other hand, tended to share care more frequently and with a wider range of people, often developing new networks for this purpose. For example, they were more likely to engage in reciprocal childminding arrangements through a 'baby-sitting circle' or voluntary playgroup. These findings can be related to aspects of stress and social network theory discussed earlier, which suggest that a close family-dominated network may create or increase stress, while a wider less dense one, comprising a number of friendships and more casual acquaintances, may reduce stress more effectively. However, Hill also comments that middle-class parents were more likely to worry about their child's emotional and psychological well-being when left in the care of others.

In summary, the limited literature in this area points to the prevalence of ambivalent attitudes among parents towards sharing care, at both formal and informal levels. This appears to be related to a number of interacting factors, such as the nature of service delivery, or structure of the informal arrangements, circumstances surrounding the event and characteristics of the child. However, the

most important factor may be a blend of cultural values and personal convictions concerning parental responsibility and childrens' emotional and psychological needs. Hill's distinction between 'inclusive' and 'exclusive' attitudes was noted. Finally, it may be speculated that parents of children with disabilities would show a similar range of attitudes to those described above, indicating a variety of differing stances towards family-based respite care.

Having considered the issues which may pertain to both carers' and parents' use of the scheme, attention should now be paid to that of the children themselves.

Attachment and Separation Theory

Reference has already been made to the prevalence of homesickness among children using residential short-term care facilities (Oswin, 1984). Although family-based respite care also hinges on the separation of child from family, it might be assumed that certain aspects of the service, such as the continuity and familiarity of caregivers, would preclude the incidence of homesickness. However, Robinson (1986) reports that about 38% of children using the Avon Family Support Service seemed to be unhappy about 'being away from home', often expressed in withdrawn or tearful behaviour, and sometimes in aggression. Studies of childminding and day nurseries have found that, even in the course of relatively brief and regularised separation, a substantial proportion of children become distressed or disturbed (Bryant, Harris and Newton, 1980; Mayall and Petrie, 1983). It was therefore considered important to examine some recent developments in attachment and separation theory and their potential relevance to the present study. It should be noted, however, that most of the literature focuses on under fives,

and often on infants, whereas children using Share-the-Care range in age from 0 to 16. The research may be pertinent to those children with mental handicap who are particularly vulnerable to separation distress because, for example, they cannot comprehend verbal speech or lack a sense of time. It may be less relevant to others whose age-appropriate social experiences enable them to react to separation as would most non-handicapped children of the same age.

It was, of course, John Bowlby who originally developed the concepts of attachment, bonding and maternal deprivation (1953, 1973) and who pointed to the dire consequences for a child's normal development and future mental health, of separation from his mother. Rather, the child needed:

... a warm, intimate and continuous relationship with his mother (or permanent mother-substitute, one person who steadily 'mothers' him), in which both find satisfaction and enjoyment.
(p.11)

Bowlby's thesis enjoyed such currency that, for twenty years, it was generally considered undesirable for a mother to leave her child in the care of others.

However, despite the vast importance of his work in drawing attention to the ill-effects of poor institutional care, other aspects of Bowlby's work are not compatible with recent advances in the theory of child development. For example, Bowlby greatly underestimated the significance of learning and the fact that positive experiences in later life, or simply the cessation of bad ones, can 'undo' any damage caused in early childhood.

Human development is a slow process of genetic and environmental interactions, with sensitivities (rather than critical periods) for different processes at different times.
(Clarke and Clarke, 1978, p.24)

Rutter (1972) showed that the consequences of poor institutional care derive from multiple deprivations and not simply separation from the mother. He rejected Bowlby's concept of monotrophy, arguing that babies can become attached to a number of caregivers and that warmth and intimacy are not exclusive to the mother-child relationship. Nor did Rutter accept that the relationship must be continuous, arguing that a young child may be able to cope with brief separations, provided a good quality of alternative care is available, preferably in a familiar environment, by familiar people and accompanied by adequate stimulation. His thesis is borne out by the reactions of the two infants, Kate and Jane, 'fostered' for a short period by the Robertsons (1971) and surviving the experience in a state of 'manageable anxiety'. Further evidence that brief separations need not be traumatic comes from Heinicke and Westheimer (1965).

The circumstances surrounding a separation also influence its impact on the child. Factors which should be taken into account include the nature of previous such experiences, the duration of the present one, and events leading up to it, family conflict or stress being most likely to evince disturbed reactions in the child (Provence, Naylor and Patterson, 1977).

Of particular relevance to the present study is research which indicates that not only can a child survive brief separations intact, he may even benefit from a variety of social contacts, each offering

a different type of stimulation. It is now recognised that children may also benefit from having a variety of stable caregivers, provided the relationships are marked by attachment, familiarity and responsiveness (Tizard, 1986). Similarly, the opportunity to play with and form friendships with their peer group can promote maturity and independence (Dunn, 1977). Within the framework of the transactional model, it is worth noting that the caregivers' ability to form a close attachment to the child will be influenced by certain characteristics of the latter, and the interacting interpretations made by each of the other's behaviour (Sutton, 1985).

However, despite the above provisos, some degree of anxiety or distress is likely to mark most children's initial separation experiences. In order to minimise and contain such distress, sensitive preparation and gradual introductions are important. Yet inadequate procedures have been found both in relation to childminding and day nurseries (Mayall and Petrie, 1983) and family-based respite care (Robinson, 1987). It has been suggested that, in order to prepare children for day care, parents might play simulation games or help them settle into new surroundings by remaining with them for some time (Provence, Naylor and Patterson, 1977). Fahlberg (1982) recommends open, active transferral of parenting, thus reassuring the child that the alternative caregiver has parental approval and can therefore be trusted. Covert or evasive tactics should not be employed. Again, during periods of separation, the ability to maintain some form of active contact with his parents, to have access to familiar objects or surroundings and to adhere to accustomed daily routines will all enhance the child's sense of security in the situation and reduce feelings of distress. Finally,

caregivers should reassure the child about his parents' return and arrangements for returning home must be carried out as promised.

In conclusion, it has been recognised for many years that children are more likely to benefit from substitute care provided in a home-like and preferably familiar setting, than from that provided in an institution. More recently, the benefits to be gained from having a range of social contacts, and from a variety of stable caregivers, have become widely accepted, provided relationships with the latter are marked by attachment, familiarity and responsiveness. However, young children are likely to undergo some degree of distress on initial separation from their parents. The resulting importance of good preparation and support and the need for openness and consistency were therefore noted.

Summary and Conclusions

Insights from several different areas of research have been brought together to form a theoretical framework for the study. Family stress and coping theory has suggested that each family is subject to a certain amount of stress as it attempts to fulfil its various functions and to negotiate a series of developmental stages. Extensive research has shown that the presence of a child with a mental handicap may act as an additional stressor. However, families are not simply passive reactors to stress. Rather, they actively seek to develop effective coping strategies. As part of this process, they may draw on external resources as a means of support. Share-the-Care may be seen as such a resource. However, while several studies indicate that the provision of external support is an effective aid to coping, it has also been pointed out that the relationship is a complex one. External resources, for example,

cannot be obtained without a relatively high degree of energy expenditure. Those under most stress may therefore be least able to secure such support. Cunningham and Byrne (1985) recommending the use of a transactional model, have called for an examination of parents' coping strategies and the resources needed to sustain them. Within this framework, a principal aim of the present study is to evaluate the effectiveness of family-based respite care in reducing stress and enabling parents to cope, bearing in mind that families are likely to differ in their levels of stress and their coping styles.

Attention was also paid to the literature which deals with the orientation of foster parents, which was described as 'traditional' or 'professional', to parental attitudes towards shared care, which may be 'exclusive' or 'inclusive', and to recent developments in attachment and separation theory. These indicate that young children may benefit from having a variety of stable caregivers, provided the relationships are marked by familiarity, attachment and responsiveness. Finally, it may be noted that research in all three areas points to the emotional and psychological complexity inherent in situations of shared care.

CHAPTER 3

Methodology

Introduction

This study was funded by the ESRC under a Collaborative award with Lothian Regional Social Work Department. Two important implications for methodology arise from this point which should be noted at the outset. Firstly, an initial research proposal had already been drawn up before I started work on the project. Although, clearly, this was open to alteration as the research issues were explored in greater detail, still it provided a basic framework for the study which remained unchanged. Secondly, access to agency records and to clients had been agreed in principle at an early stage. Not only was this a considerable advantage in relation to the time-scale of the research, but the co-operation of the agency as a whole and of individual social workers greatly facilitated the research process.

This chapter begins by outlining the theoretical considerations which informed the study's methodology. It moves on to discuss the advantages and disadvantages of various research methods, setting out the reasons which determined the use of some and the exclusion of others. The second half of the chapter contains a more descriptive account of the research process in practice.

Theoretical Framework

In the preceding chapter, it was noted that sociological research seeks to describe, analyse, and interpret social phenomena and to do so by using an appropriate theoretical framework. Such a framework, as already mentioned, consists largely of 'small-scale' theory (Silverman, 1985) arising out of the specific research aims,

By whom?

but has as its basis a wider-ranging perspective concerning the nature of social reality. Such a perspective should be one which, again, is capable of addressing all the research aims; secondly, takes account of ethical considerations, particularly in relation to methodology and, thirdly, is compatible with the personal viewpoint of the researcher. However, its most important implications may be methodological. Worsley (1977) is one of many writers to point out that decisions about research methodology cannot be taken purely in terms of 'techniques', but

... rest on prior assumptions, often of a philosophical nature, about human relationships, the legitimacy of making general statements about behaviour and the whole notion of 'science' as applied to society.
(p.73)

The arguments against the application of positivist approaches to social science research have been well documented elsewhere (Weber, 1949, 1957; Cicourel, 1964; Fay, 1975) and will not be rehearsed in detail here. In particular, it has been pointed out that a conceptual framework and methodology appropriate to the natural sciences cannot be transposed on to the social sciences, since the two spheres are radically different in nature. Positivism assumes the existence of objective truth, of a single, external reality which lends itself to assessment through objective measurement (McNeill, 1985). Proponents of positivism would argue for the use of a hypothetico-deductive model, conducting experiments in which they seek to control and manipulate variables in order to arrive at causal explanations and predict future outcomes. Clearly, there are grounds for both ethical and practical objections to using

this method within a 'natural setting' of human actions and relationship, such as the Share-the-Care Scheme. Sainsbury (1983) has challenged the application of positivist techniques to social research because they

... relegate the client to the status of an object within experimental designs, an object in whom, or on whose behalf, changes can be predictably wrought by the scientific application of external resources and skills.
(p.4)

Again, positivism assumes the possibility of an objective, value-free approach to social science (Fay, 1975). However, adopting an 'objective' stance towards the evaluation of social services would imply a disregard of both the moral values and the political and social dimensions which are inherent within the theory and practice of social work (Sainsbury, 1983). The effectiveness of service delivery cannot be measured purely in terms of facts and statistics since it hinges on certain ideological and ethical considerations, such as concepts of 'need' and 'client satisfaction', which underlie the provision of such services (Philips, 1983). Finally, from the positivist perspective, human action is seen as governed and controlled by certain fixed laws (i.e. the framework of society) in relation to which individuals stand passive, like reeds blown by the wind.

In opposition to this view, interpretive sociology, derived from the work of Mead (1925, 1934) and Weber (1949) suggests that social order is in a constant state of flux and change, subject to no predetermined pattern. It conceives of man as a self-conscious,

active being capable of attributing a wide range of subjective meanings to the social phenomena around him. Social action is therefore seen largely as the consequence of actors' interpretations both of their own situations and the actions of others, while human behaviour is best understood in terms of the perceptions, rules and meanings according to which people order their own reality, rather than by extraneous factors beyond their control. Thus, there is no single social reality but a myriad of different, perhaps conflicting, realities, which vary according to the viewpoint of the individual observer. In this sense, it is a social construct (Berger and Luckman, 1967) which cannot therefore be objectively measured nor predicted. Rather, the actors themselves are considered to be the most important and reliable source of information about their own lives. Data obtained from them is, again, subject to the researcher's own interpretation of it (Fay, 1975).

This understanding of human behaviour and social reality is central to those aims of the present study, outlined in the previous chapter, which are concerned to explore the values, beliefs, perceptions and attitudes of scheme users. Furthermore, the theoretical framework outlined in the preceding chapter for the substantive issues of the research, places great emphasis on the ability of families to actively create coping strategies, rather than passively reacting to stressors as they arise. Similarly, stress and coping theory has drawn attention to the central role of subjective perceptions in determining a stressor's impact on family functioning and as a potential coping resource. Thus, in order to complement the content of what Silverman (1985) has termed the 'small-scale theory' informing the study, an interpretive perspective has much to offer.

However, the study has other aims concerned with factors somewhat more tangible than the nature of subjective perceptions. For example, in seeking to explore the reasons why some families remain on the scheme's waiting-list for many months, it seems reasonable to suppose the existence of possible causal factors other than the actors' own definitions of the situation. In seeking to yield findings which will be applicable to similar services, I am assuming the existence of possible relationships and processes which are independent of the situated context of individual matches or schemes. Again, the study is centrally concerned with the operation of one social organisation, the Share-the-Care Scheme, which has a distinctive structure made up of norms, procedures, practices and ascribed roles, and it is closely concerned with another - the family. Both organisations may be subject to the influence of wider social structures, such as economic and political factors. Thus, the study aims both to explore the subjective perceptions of respondents and also to evaluate the operation of social organisations. Nor should these two aspects be viewed as separate, since the former objective also acts as a strategy for achieving the latter. It has been argued that subjective perceptions not only interpret and give meaning to the social structures around them, but may also be partially shaped by them (Silverman, 1985). Indeed, this process may be conceived as a transactional one.

In effect, sociology's long-running 'wars of religion', as McNeill (1985) has termed the debate between its different schools, has now given way to a widespread acceptance of using a combination of theoretical and methodological approaches in research. This is known as 'triangulation', a term originally used to denote the

process of surveying land by breaking it up into connected triangles, but first applied to research methodology by Campbell and Fuke (1959). In relation to the social sciences, triangulation involves

... the recognition that, while peoples' actions are a result of their interpretation of a situation, their interpretations and their choices are limited by structural factors external to them and beyond their control.

(McNeill, 1985, p.115)

Denzin (1970) suggests that triangulation can be effected at three levels - theoretical, methodological and analytical, in an effort to avoid the kind of bias likely to occur in studies which employ only one method of data collection. In the preceding chapter, a variety of theoretical perspectives were brought together to form a single conceptual framework. In relation to methodology, again a number of strategies may be employed, in this case with a primarily qualitative focus. A vital element in such an approach is the use of semi-structured interviews which, again, are capable of addressing a single topic from a variety of angles, thus building up a fuller perspective on the research issues. Fisher, Marsh and Philips (1986) have shown how a combination of narrative techniques, whereby respondents are invited to give their own open-ended accounts of events, along with an element of more focused, structured questioning, may obtain a width and depth of data unlikely to emerge were only one level of interviewing employed.

Finally, it may be noted that a synthesis of methods has been used in several studies whose aims are similar to those outlined for the present research. Robinson (1987), for example, in her evaluation of the Avon Family Support Service, employed structured interviews, postal questionnaires and agency records, while Fenwick

(1986), in a study of the Newcastle Face and Stop Schemes, also combined three sources of data - structured, interviews, descriptive statistical records and a group discussion with clients.

Choice of Methods

On the basis of the considerations outlined above, it was decided that a triangulated approach would be the most appropriate method for the study, with the emphasis mainly on qualitative aspects. In line with several other studies concerned to elicit the views of parents with handicapped children, (Lonsdale, 1978; Hunter, 1980; Venters, 1981) the principal method of data collection would be through semi-structured interviews. Unfortunately, limitations of time and resources restricted the extent to which other methods could be employed. However, it was decided to supplement the interviews with data obtained from a postal questionnaire sent to professionals, examination of agency records and small-scale use of observation. The decision to employ these methods also involved choosing to exclude others. I shall now try to outline the bases on which such judgements were made.

(i) Semi-Structured Interviews

The use of unstructured and semi-structured interviews emerged as a key strategy for data collection during the 1960s and 1970s. To a large extent they supplanted the more formal structured interview and the large-scale survey. A growing conviction in the authenticity of actors' own perceptions required researchers to develop a method which allowed more direct communication with their subjects (Brenner, Brown and Canter, 1985). There are areas of potential difficulty, however, in relation to their validity (the extent to which they successfully measure those items which they are intended to measure)

and reliability (the extent to which their findings are replicable).

Firstly, it has been argued that elements of bias or inaccuracy may enter respondents' accounts. This claim is partly based on the simple observation that the relationship between 'saying' and 'doing' is often incongruent (Ackroyd and Hughes, 1981). Past events may be misrepresented through memory loss or with the benefit of hindsight, while future intentions may be miscalculated as a result of unforeseen circumstances or other sources of uncertainty. Although most people probably like to perceive themselves as honest, yet there may be a tendency to present one's motivations and actions in a favourable light and to give an account of oneself which will be 'socially acceptable'. Again, it is argued, respondents who are reluctant to convey the impression that they lack knowledge of, or opinions about, a given subject may offer inaccurate information as a means of compensation (Ackroyd and Hughes, 1981).

Secondly, elements of bias may arise from the wording of the questionnaire. Oppenheim (1966), for example, warns against the use of 'loaded' or leading questions. It may be argued that these dangers are greater in a structured, rather than semi-structured interview. Closed questions, fixed-choice responses and attitudinal scales can serve as little more than useful pointers to the real nature of actors' feelings, beliefs, opinions and values. Equally, they run the risk of imposing on subjects' the researcher's own frame of reference and are likely to limit their ability to report on aspects important to them, or to convey in depth the meanings they ascribe to social actions. As Brenner (1985) has pointed out, pre-coded questionnaires wrongly assume 'a total equivalence of meaning' among respondents and may lead to misunderstandings or

misinformation. In short, this method is better suited to large-scale studies designed to test specific hypotheses and those which seek to yield findings primarily of statistical rather than theoretical significance (Ackroyd and Hughes, 1981).

Semi-structured questionnaires, on the other hand, contain a substantial proportion of open-ended questions, allowing for a wide-ranging exploration of potential areas of significance and giving respondents more freedom in which to develop their own frame of reference. This format enables the interviewer to start where the respondent 'is' and then to move freely around the questionnaire in tune with the drift of the conversation. At the same time, the researcher can ask a number of questions on a single or related topic in a variety of ways, thus building up a fuller understanding of the complexity of her respondent's perceptions. She can use probes and prompts when areas of potential significance are indicated but not fully explicated. Semi-structured questionnaires allow both respondent and interviewer to clarify meanings if and when necessary during the course of the interview. Because of these facets, McGlew (1983) suggests that the validity of data collected in the small-scale qualitative study is enhanced by its ability to reflect the 'complex connectedness' between variables. In order to secure comparability of results, however, the interviewer must ensure that each question has been answered. If necessary, this can be effected at the end of the interview by checking through the questionnaire. It is more difficult to attain comparability in unstructured interviews, in which the research is guided only by a list of general topics.

Besides the wording of the questionnaire and the way it is

administered, many commentators have drawn attention to the importance of the manner in which the interview is conducted, again as a means of increasing reliability and validity (Benney and Hughes, 1977). Stacey (1969) suggests that attention should be paid to the significance of non-verbal cues given by respondents, such as gesture and facial expression, and to the implications of manner and tone. Merton and Kendall (1946), in their advocacy of the 'focused interview', suggest that an important task for the researcher is to continually evaluate the interview as it proceeds, reacting accordingly in order to ensure its objectives are met. For example, she should be ready if necessary to alter 'the level of depth' on which her respondent is operating. Oakley (1981) and Finch (1984), however, challenge such prescriptions as essentially manipulative 'male' techniques, in favour of a more 'honest' or straightforward approach in line with feminist methodology. ?

Merton and Kendall's perspective on the interview was also challenged by Cicourel (1964), who pointed out several seemingly incompatible features, some of which may apply to semi-structured questionnaires. As noted above, for example, Merton and Kendall advocate that the researcher should convey an impression of non-directiveness while simultaneously employing some highly manipulative techniques. In particular, Cicourel argues that the use of 'basic theory' (or 'commonsense' thinking) which is a vital element in conducting the interview, may be at odds with the 'scientific theory' employed by the researcher at a more conscious level. Thus, Cicourel first drew attention to the interview as a social encounter like any other, a process of interaction between two individuals who bring to it their own meanings, definitions and 'commonsense' knowledge. He ethics

points out that 'error' is likely to occur as a natural element within any such interaction, resulting from individuals' subjective reactions to one another. Differences between interviewer and respondent in terms of their personal and social characteristics, particularly in relation to age, sex, social background and race are likely to increase the risk of bias and decrease the level of reliability. Cultural differences may lead to misunderstandings on either side. Again, one party may define the other in terms of a 'social type' and react accordingly. Conversely, over-identification may also threaten the validity of the data obtained, by leading the respondent to answer questions in a way which he imagines is likely to please the interviewer. As the interviewer cannot attain identical rapport with each respondent, her findings, so it is argued, are unlikely to be reliable.

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On the other hand, there may be a number of ways in which the interviewer can minimise these difficulties and establish good rapport with her respondents. An obvious starting-point would be to ensure a reasonable degree of compatibility between both parties, in terms of social characteristics. Oppenheim suggests that the interviewer should avoid strongly agreeing or disagreeing with her respondents, but should convey a sense of interest in, empathy with and uncritical acceptance of both them and their accounts. Ackroyd and Hughes (1981) identify trust, reassurance and 'likeableness' as the main qualities the interviewer needs to communicate if respondents are to feel secure about imparting information which they might not otherwise give to a stranger. People tend to enjoy an opportunity to talk about their experiences, or air their views, to a sympathetic listener who does not challenge them. Oppenheim suggests

that the more 'involved' the subjects become, the more valid their accounts are likely to be. These factors make this method of data collection particularly suitable for potentially sensitive matters, again recommending it to the present study. Some respondents might find it difficult to discuss their feelings about parenting a handicapped child, for example, or their anxieties about sharing care.

It might be argued that conducting joint interviews with husband and wife is likely to invalidate the data obtained. Some studies have found that not only do men tend to dominate discussion (Spender, 1980) but they may even offer inaccurate information about domestic matters with which they are less familiar than their wives. For example, Backett (1982) found that fathers tended to overestimate their contribution to childcare. Bryant (1984) suggests that either partner may be inhibited by the other's presence, withholding information as a result or else presenting it in a way which will meet the other's approval. On the other hand, partners can stimulate each other's thoughts through reinforcement or disagreement, reminding each other of events or experiences which might be omitted from separate interviews (Jenkins, 1975). Evaluative studies of social services which have been content to interview whichever parent(s) was available at the time, have been criticised for lack of rigour (Philips, 1983). Involving fathers in semi-structured interviews also serves as a recognition of their contribution to family life (Hill, 1984).

Philips has pointed to the dangers of interviewing families retrospectively about service utilisation. Results may become biased through memory loss, the effects of intervening events, or the

operation of hindsight. Similarly, Sutton (1985), in her proposals for a further study of the Avon Family Support Service, points out that development is a dynamic process and that patterns of behaviour and the nature of perceptions are liable to change over time. She concludes that an evaluative study of family-based respite care should be conducted longitudinally. In relation to the present study, it was considered important to conduct prospective interviews in order to heighten the validity of the data and to assess more effectively the impact of the scheme on user families.

Other methods of enhancing the validity and reliability of semi-structured interview data include rigorous sampling procedures, the use of an interjudge and a full explication of the analytic process (McGlew, 1983). Questionnaires can be pre-tested through pilot interviews. The extent to which findings are comparable to those of similar studies is another possible means of verification. These matters will be fully dealt with in subsequent pages.

Implicit in much of the preceding discussion is a number of theoretical considerations regarding the nature of the interview situation. Cicourel is suggesting that data thus obtained cannot be viewed as objective reports on an external reality but, rather, that they reflect an internal reality constructed by interviewer and respondent during the course of their interaction. As such, they are not necessarily reflective of anything else. In this context, 'errors' and 'bias' cannot be viewed as threats to validity or reliability but are seen as having a validity of their own which serves as a subject for, not a tool of, investigation.

However, Silverman (1985) has challenged the positivist, interactionist and ethnomethodological approaches to interview data

on the grounds that, to put it simply, each addresses only one manifestation of reality. Instead, Silverman points to the 'realist' perspective of Bhaskar (1979) as providing a framework which recognises the co-existence of external structures, subjective meanings and internal constructs. He suggests that interview data should be treated as 'displays of reality, neither biased nor accurate', but which reflect social structures expressed in terms of subjective perceptions, within the framework of conversational practices. His thesis provides a useful backdrop for the present study which, as already outlined, requires a methodology capable of addressing the 'transactional' process between subjective perceptions and external structures. The aims of the research will not, however, require examination of interview data in terms of internal constructs, interesting though that might be.

(ii) **Standardised Tests**

Several studies involving semi-structured interviews with parents of handicapped children have also administered some form of objective, standardised testing procedure, most notably the Maternal Malaise Inventory developed by Rutter et al (1970) (Pahl and Quine, 1985; Wishart, Bidder and Gray, 1981; Chetwynd, 1985). As mentioned in Chapter 2, this is a 24-item, binary choice schedule, designed to determine the existence or absence of certain physical ailments and emotional responses generally associated with stress. Use of this instrument would have allowed for ease of comparability with related research, as well as a convenient means of assessing the scheme's effectiveness in reducing stress, or so it seemed.

However, the Inventory makes no attempt at causal analysis, and therefore it would not be possible to infer either that levels of

stress measured before joining the service were necessarily related to the demands of caring, nor that those measured afterwards were linked to service utilisation. Use of the Inventory implies that the development or reduction of stress is likely to be related to a single factor, suggesting a simplistic cause-and-effect conception of stress, which fails to address its complex and cyclical nature and is clearly at odds with the insights of stress and coping theory.

The scale is designed to give equal weight to a number of different 'symptoms' which, it might be argued, vary in significance. This may adversely effect the comparability of individual scores. The validity of the test could also be challenged on the grounds that it may register the physical rather than emotional effects of caring for a handicapped child. Backache, for example, may result from constantly lifting a heavy, non-ambulant child and is not necessarily related to levels of stress. The wording of certain questions, which include phrases such as 'often' or 'usually' is open to differing interpretations, although the Inventory is designed to be self-administered. Vernon (1964) has pointed out that because some items refer to the past, rather than the present, they may elicit outdated or irrelevant information. Data may be further distorted by the Inventory's fixed-choice format.

Finally, I felt some discomfort about using the Inventory because it seems to imply a peculiarly negative view of both the child's impact on the family and of parents' coping abilities. I believed some parents might be offended as a result. It is interesting to note that Sutton (1985) has sounded a caution against using insensitive methods to broach sensitive issues within this field of research; for example, there seems little theoretical or

ethical justification for asking parents if they would now terminate a pregnancy if they knew a handicap was present, a question posed by Pahl and Quine (1984). The final decision against using the Malaise Inventory for this study was taken when social workers within the agency were found to share my reservations about parental reactions.

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(iii) Postal Questionnaires

As mentioned earlier, a number of studies in this field have used postal questionnaires as a supplementary, rather than principal, data source (Robinson, 1986; Bird, 1982). Consideration was given to sending a postal questionnaire to professionals who had referred clients to the scheme, in order to elicit their perceptions of the service and to compare their views with those of its users.

Postal questionnaires clearly raise certain difficulties, which have already been outlined in relation to structured interviews and surveys. In particular, they do not allow their respondents an opportunity to develop their own frame of reference, nor to clarify meanings. In order to minimise the latter difficulty, Stacey (1969) suggests their wording must be clear and unambiguous. Nor is there any reason why questions should not remain open-ended, rather than taking a fixed-choice, pre-coded format.

Another possible drawback of postal questionnaires is that recipients may lack the motivation to complete them. Unlike face-to-face interviewing, which may carry certain rewards for respondents, postal questionnaires offer little direct feedback. The length of the survey and expected depth of response are also likely to affect rates of completion. On the other hand, Jenkins (1975) suggests they may be suitable for a homogeneous group, while Stacey notes their appropriateness for respondents who have a specialised knowledge of

the subject-matter of the research. Both conditions were thought to apply to professionals making referrals to Share-the-Care.

A most important practical consideration was time. Having decided to conduct semi-structured interviews with scheme users, it would have been quite impossible to do the same with professionals, especially as the latter sample was estimated to be between 30 and 40. Again, it was felt that the data obtained from postal questionnaires could be used to support, supplement and contrast with that collected in the interviews, rather than being presented as a separate set of findings in itself. Finally, by using open-ended questions and allowing space at the end for respondents to develop their own ideas, it was hoped to lessen some of the difficulties of a structured format.

(iv) Participant Observation

Another means of collecting data sometimes combined with semi-structured questionnaires is participant observation, a method derived from anthropological field studies of the early twentieth century and made famous by the Chicago School, headed by Robert E Park. This method, drawing on insights from symbolic interactionism, stresses the interactive and negotiated character of social action (Bruyn, 1966).

However, participant observation has been criticised for its unsystematic techniques of data collection and the danger of the researcher imposing subjective interpretations on data; that is, it lacks criteria of validity and reliability (Ackroyd and Hughes, 1981). The phenomenon of 'observer effect', whereby the researcher unconsciously influences the social processes and behaviour which she is observing, may distort the data obtained. Conversely, once she

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has established a role within the group, she may find it increasingly difficult to maintain an objective or detached perspective. 'Going native' is an extreme outcome of this process.

Apart from these considerations, the fact that participant observation requires the researcher to involve herself directly in the lives of her subjects precluded its feasibility for this study. The Share-the-Care Scheme provides care on an individual basis within the carer's own home. There can be little or no scope for the researcher to adopt a 'role' or social identity within this setting. Again, even as a passive observer, it was considered that the effect of an observer's presence on the behaviour of others would be too pronounced. It might have been possible to use participant observation within the agency, firstly, had the focus of the study been on the interaction or activities of social workers and, secondly, if staff numbers were higher. During most of the fieldwork period, however, only two social workers were employed on the scheme.

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On the other hand, it was considered most important to spend a certain amount of time within the agency, especially within the early stages of the study, in order to become familiar with details of the scheme's operation. This period (which is a requirement of a Collaborative Award) would help to identify and sharpen the research issues to be explored with scheme users during interviews. It was not intended to undertake a systematic observational study of the team itself, either from an organisational or interactionist perspective.

(v) Agency Records

McNeill (1985) points to the usefulness of secondary data as a means of familiarising oneself with the research issues and of

supplementing that obtained from other sources. The initial research proposal indicated that extensive data should be collected from agency files and records about the planning, administration and operation of the scheme. However, it emerged from closer examination that the amount of comprehensive, written information about those aspects of the scheme was limited. This finding probably reflects the fact that the scheme originated at 'grass roots' level, arising out of the practice experience of an area team, rather than from prolonged policy discussions at managerial level. Similarly, the nature and extent of information about scheme users - parents, children and carers - proved to be highly inconsistent, some files containing little more than the original application form, while others were much fuller. Again, this finding is not insignificant: it probably reflects the agency's perspective that scheme users are not 'clients' and that the social work task does not involve 'casework'. In short, the amount of useful information which could be collected from agency files was considerably less than had originally been envisaged. Nevertheless, some data was obtained which served two important purposes. Firstly, it provided factual information about the personal and social characteristics of scheme users. Secondly, social workers' written comments offered additional perspectives on aspects of interview data. These were not used to test the 'accuracy' of users' accounts but, in line with Silverman's thesis (1985), were seen as alternative perceptions with a validity of their own.

The Research Process in Practice

Having outlined the reasons why a certain combination of methods was chosen for the study, the rest of this chapter records how it was

carried out. To a large extent, this will be a descriptive account, although the practical and methodological considerations which informed a number of decisions taken at various stages of the process will also be discussed. Although different aspects will be presented separately for the sake of clarity, in reality various strands of thought and activity interacted with each other and occurred simultaneously, or, at least, not in the neatly ordered sequence perhaps implied by presenting them in this way.

Sampling Procedures

The Inclusion of a Contrast Sample

It was originally hoped to include a contrast sample of parents using hospital-based provision for respite care. The principal objective for introducing such a group was to explore the reasons why different families make use of different facilities. The characteristics of the two groups could be compared and any differences identified; the bases on which decisions and (if applicable) choices were made could be examined, and parental perceptions of each service contrasted. Oswin's study of residential short-term care (1984) includes a small-scale examination of family-based schemes.

Consideration was therefore given to seeking a sample of parents whose children received respite care within the Special Care Unit of a local mental handicap hospital. Further enquiries, however, revealed that the current rate of regular respite admissions at that hospital was relatively low and that children were more likely to receive short-term care in a unit for convalescing children attached to a local paediatric hospital. Attempts were made to gain access to parents using this facility through a number of written approaches to

the consultant concerned. Unfortunately, these did not meet with a positive response and, after several unsuccessful attempts, over a number of months, to move the negotiations forward, the proposal to include a contrast group was, reluctantly, dropped.

Parents as Applicants

One important point which greatly affected decisions about sampling procedures should be noted at the outset. Once the decision had been made to conduct prospective interviews with parents, before and after using the scheme, the ability to achieve this objective was dependent on a number of factors connected with the scheme's operation and outwith the researcher's control. These included the rate of referrals to the service, the rate of referrals to the study, the ability of social workers to 'match' parents to carers, the time-scale in which this was achieved, and so on. Unfortunately, real life events do not always match the research proposals designed to accommodate them, in which case the research proposal must be altered to take account of changing circumstances.

Three main considerations guided sampling procedures for parents as applicants. Firstly, as the study was exploratory and the interviews semi-structured, designed to elicit mainly qualitative data, it was necessary to have a small sample. Secondly, because interviews were to be prospective, limitations of time and resources also argued for low numbers. Thirdly, rate of referrals to the agency was a vital factor. This was reported by social workers as unpredictable, but likely to be slow. In order to attain a viable sample, it was therefore decided to include all new applicants, with a target quota of 15. Social workers within the agency agreed to supply the names and addresses of these families. When a referral

was received from an external professional who held continuing responsibility for the case, access would be requested through her/him.

However, some new applicants were excluded from the study, for one of three reasons. Firstly, in two cases, external professionals appeared reluctant to give access to families which were highly stressed, on the grounds that it was unfair or unreasonable to ask parents in these circumstances to cope with the demands of taking part in research. It is interesting to note that Share-the-Care staff took a different view, stressing the importance of including such families in the study. The difference may be related to external workers' greater familiarity with details of specific families' situations, as well as some feelings of protectiveness towards clients and/or the agency's greater familiarity with, and commitment to, the research.

Secondly, in discussion with social workers, one or two cases were excluded on grounds of unrepresentativeness. This included an application for respite care on a one-off basis and another for a child living in a residential school who required placement during holidays. A third application and referral was withdrawn following an incidence of suspected N.A.I.

Thirdly, two families decided against participating in the research, one, because they had recently felt 'over-exposed' to contacts with 'professionals', the other was a single parent who 'opted out' for reasons unknown, but possibly connected to the various demands of her current situation.

In short, it is possible that sampling procedures applied to parents may have resulted in a slight element of bias, due to the

exclusion of a small number of families (perhaps four) thought to be under severe stress. It is worth noting that subsequent analysis of this sample in terms of levels of perceived stress suggests an even distribution of 'low' and 'intermediate' levels but slightly fewer families perceiving themselves as highly stressed. While it is important to bear this factor in mind, there is no evidence to suggest it resulted in serious distortion of the sample's representativeness.

As mentioned above, a target figure of 15 was originally set for this sample. However, four largely unforeseen factors resulted in the increase of this number to 30. Firstly, once the fieldwork started, it became clear that some families were not being linked to carers as quickly as had been imagined. Social workers indicated some difficulty in finding carers for these families. Clearly, this had serious implications for their ability to participate in follow-up interviews about service utilisation and for the time-scale of the fieldwork. Secondly, it emerged that some families who had participated in initial interviews were in fact withdrawing from the scheme, either before or after being linked to carers. Thirdly, as described above, the proposed inclusion of a contrast group had to be dropped. If these developments all appeared alarmingly detrimental to the research design, a fourth factor emerged which had more hopeful implications. After a slow start, the rate of applications to the scheme - and thus referrals to the study - greatly increased. The emergence of a significant number of 'withdrawals' seemed to warrant further investigation, as did the fact that some families remained on the waiting-list for many months. It was therefore decided to retain the original plan to conduct follow-up interviews

with all the families, but to divide them into three different samples, depending on the outcome of their applications: 'parents as consumers', 'parents who wait' and 'those who withdrew'. Interviews with those who were not using the service would focus on reasons for, and perceptions of, these particular outcomes. It was also considered important to retain some comparative element in the study. For this reason, it was decided that analysis would include some comparison of data obtained from both sides, parents and carers, of 15 matches. In order to make this possible, and to achieve a viable number in each of the three 'outcome' samples, it was decided to increase the target number within the applicants' sample to 30.

The majority of these families were interviewed within a few weeks of submitting an application to the scheme. One had used the service for an overnight stay, a few had been introduced to potential carers, but most had not. As the questionnaire used for this interview focused on parents' experiences of bringing up the child and on various aspects of family life, the fact that respondents were at slightly different stages within the procedure was not considered problematic.

Parents as Consumers

Fifteen parents from the original sample of 30 applicants fell into the consumer sample. The criteria for inclusion in this group were, firstly, that matching procedures had begun within six months of the first interview and, secondly, that the families were still using the scheme 6-8 months after being matched, at which point the follow-up interviews took place. For the purposes of this study, the date on the carers' first returned 'fee claim' form was taken as the beginning of the match.

However, there was tremendous variation between cases in the length of time matching procedures took to complete. This depended on a number of factors beyond the researcher's control, particularly the amount, frequency and timing of introductory meetings which took place before the child's first 'official' visit, at which point a fee claim was returned by her carers. Again, about six months after initial interviews, a social worker might indicate that potential carers had been identified for a particular family, who should not therefore be excluded from the consumer sample. Yet matching procedures might not be implemented for several weeks. As a result of these contingencies, some parents were included in the consumer sample who had not been matched within six months of the previous interview. Two families had waited considerably longer.

All 15 parents agreed to participate in follow-up interviews.

Another family had been matched within six months of initial interview but unfortunately their carers were forced to withdraw from the scheme, for family reasons. This family was not therefore included in the consumer sample.

Parents who Wait

This sample consisted of five families who were still waiting for carers 7-10 months after their initial interviews. When social workers reported no prospect of matching a family six months after the initial interview, they were placed in the 'waiting' sample. One mother, feeling highly stressed due to a temporary marital separation, postponed the follow-up interview for three months. Another family 'opted out' of a second interview; they, too, were under considerable stress. Sadly, one of their children had died in the intervening period.

Parents who Withdraw

Nine families from the original sample of 30 applicants withdrew from the scheme during the fieldwork period, three of whom had been linked to carers and, in these cases, between one and four visits had taken place. The other six families had not reached the 'matching' stage (although one had been introduced to a possible carer) and withdrew between three and seven months of applying.

Follow-up interviews with these families took place between a fortnight and six months after the family withdrew, although eight weeks was about average. Two main factors account for the variation in timing. Several cases of 'confused status' emerged, by which I mean that while the family considered their application closed, the agency continued to classify it as active. Thus, it happened that I would set out to interview families still on the waiting-list, only to discover they had, in effect, 'withdrawn' their applications. Secondly, it was originally decided to treat one or two 'withdrawals' as losses, but later it became clear that withdrawing from the scheme was a significant factor, requiring further examination. Two families therefore had to be interviewed retrospectively.

Eight of the nine families agreed to participate in follow-up interviews. The remaining family was not approached, as the parents had separated and the child received into long-term care.

Carers

It was decided to interview the carers matched to families in the consumer sample, in order to attain both perceptions of an individual match and allow for some comparison of data in analysis. It was considered important that both sides be interviewed as

closely together as possible. Thus, nearly all 15 carers were seen within 0-14 days of the parents to whom they were linked.

In order to attain a viable sample of carers and to explore some broader aspects of caring, a further 15 were interviewed, linked to families who were **not** involved in the study. These carers were chosen by random sampling. Excluding those matched to the consumer families, every second carer, as listed alphabetically in agency files, was interviewed, until the required quota was reached. The same questionnaire was used for the total sample of 30 carers - giving greater validity to its findings, while also allowing for some simple numerical counting.

In addition, two carers were interviewed whose matches had ended when the parents decided to withdraw. As mentioned before, another carer took part in the study after having been forced to withdraw from the scheme for family reasons. However, as she was the only one who withdrew during the fieldwork period, this line of enquiry could not be pursued.

All 15 carers linked to parents in the consumer sample agreed to take part. Two others declined to do so or, rather, attempts to include them in the sample were abandoned after arrangements to interview them were repeatedly cancelled or postponed.

Table 3.1 outlines the various samples involved in the study, while Table 3.2 refers to the timing of their interviews.

TABLE 3.1 Samples Involved in the Study

Parents		Carers	
Initial Interviews	Follow-up Interviews		
30 applicants	-->	15 consumers	<-- matched to --> 15 carers
		8 who withdrew	<-- matched to --> 2 carers
		1 was matched	<-- to --> 1 carer (who withdrew)
		4 who waited	-
		2 unavailable	-
		-	15 carers (random sample matched and 'non-study' families)
30		28	33

Full total of interviews = 91

Table 3.2 Timing of Interviews

Samples	Dates	
Parents as applicants	March 1984	- March 1985
Carers	June 1984	- October 1985
Consumer sample	November 1984	- October 1985
Parents who wait	February 1985	- August 1985
Parents who withdraw	February 1985	- October 1985
Total fieldwork period	March 1984	- October 1985

Questionnaire Design

Various activities which took place during the initial stages of the research stimulated consideration of the issues to be raised in the interviews. The study of related literature, identification of areas which required further examination and the development of a theoretical framework all contributed to the early formulation of possible questions. As mentioned above, a substantial amount of time was spent within the agency, attending a number of formal meetings and presentations, accompanying social workers on visits to users' homes and observing a full series of carers' preparation groups. I also occupied a desk within the agency and was party to many informal discussions held by the staff about the scheme. These activities played a vital role in developing and sharpening ideas about the subject matter of interviews.

Questionnaires should be designed with two main points in mind: the precise purpose of asking a specific question (to ensure that its wording will elicit the type of information required) and, secondly, the means by which it is intended to analyse data (Oppenheim, 1966). In this case, it was considered important to ask different types of question, some of which would elicit 'factual' material (for example, about the extent and nature of informal support parents received) and others which would explore respondents' perceptions, values and attitudes (for example, how easy they found it to seek informal support, the reasons why they considered it easy/difficult). Again, the questionnaires were intended to produce a mixture of quantitative and qualitative data. The former would allow for some conclusions to be drawn about the incidence of findings, illustrated by simple counting procedures, and numerical tables; the latter was considered

particularly relevant to a more in-depth exploration of meanings and definitions. At the same time, it was envisaged that data would be fed onto a computer and analysed, as far as was appropriate, with a statistical package.

The questionnaires (reproduced in full in the Appendix) therefore contained a majority of open-ended questions, allowing respondents some scope in which to develop their own frame of reference. In practice, these questions were often supplemented as necessary by the use of additional ones and, where required, by probes and prompts. Care was taken to remain alert to aspects of the discussion given special emphasis or particular significance by respondents: these were followed up accordingly. The extent to which parents felt free to identify important areas is reflected in the fact that about half the sample of 'applicants' offered detailed accounts of events surrounding the birth of their child and/or the diagnosis of handicap, although no questions on these subjects were included in the questionnaire.

At the same time, a significant number of more focused questions were also included. These can be used to elicit factual information about different aspects of the same topic. Care was taken to avoid making use of loaded or leading questions, and questions were worded as clearly as possible, avoiding jargon. In a few cases a range of possible answers was suggested in order to clarify the type of information sought. For example, carers were asked how they saw themselves in relation to the child; whether, for example, they were 'like aunt and uncle, substitute parents, family friends or something else?' It was noticeable that respondents sometimes rejected the categories suggested, either by giving an alternative answer or by

refusing to 'label' their perceptions of the relationships. In this way some questions were binary in form, but followed by an open-ended item to allow for amplification of the previous response. This proved a useful device in eliciting information which might otherwise have been lost. For example, having asked parents if they thought their child was ever homesick at the carers, those who replied in the negative were then asked how they would tell if s/he was homesick. Subsequent discussion sometimes yielded findings quite different from those implied by a simple yes/no response to the first question. On just one occasion was use made of a printed card, when parents were asked, as a final item, to indicate on a five-point attitudinal scale, how satisfied they felt with the service. The validity of information elicited by this type of question has been widely challenged, particularly in relation to evaluating services (Fisher, 1983), and indeed responses obtained implied a highly positive view of the scheme not wholly in accord with the rest of the data.

Ackroyd and Hughes (1981) refer to the importance of 'sequencing' questions in such a way that the interview opens with relatively straightforward and non-controversial topics. It is hoped that starting in this way will help establish trust and rapport between interviewer and respondent. More sensitive topics can then be introduced at a later stage, when respondents may be more inclined not only to answer them, but to do so as fully as possible. Following this prescription, for example, in the initial interviews with parents, opening questions usually centred on practical aspects of the care routine, moving on to use of informal supports. More sensitive issues, which parents might experience some difficulty in discussing (and the interviewer in raising) came later; for example,

emotional health, marital relationships and feelings about parenting a child with disabilities.

A further consideration which governed questionnaire design was the need for comparability between data obtained from different samples. Thus, parents were asked a number of questions related to levels of stress and coping both before and after making use of the service, in order to facilitate assessment of its effects. During initial interviews, they were asked a number of questions relating to their application to Share-the-Care, particularly their motivations for joining and the effects which they envisaged it might have on their lives. By pursuing these points in the follow-up interviews, it was hoped to determine the scheme's successfulness in meeting parental expectations. Carers and parents were asked about 20 identical or similar questions regarding their perceptions of the match in order to explore the extent of congruence or disagreement both within individual matches and between the two groups as a whole. Again, parents whose application to the scheme met with differing outcomes were asked a number of similar questions, thus allowing for some comparison between the experiences of those who received the service, those who waited and those who withdrew.

A final point should be added about the questionnaire designed for parents' initial interviews, which concentrated on their experiences of bringing up the child, the effects of caring on other areas of family life and aspects of stress and coping. In planning the wording of questions, efforts were made to avoid implying any negative assumptions about the nature of family life and, specifically, suggesting that the child might be a 'burden'. Various studies which had adopted a 'pathological' approach (Wilkin, 1979)

have been guilty of this fault. Care was taken to give parents a chance to express their positive experiences (for example, 'what sort of rewards and pleasures has Jenny brought you?') as well as those which might be more difficult ('Does his/her behaviour cause any particular problems?')

In all, four different questionnaires were used for the bulk of the study, namely, one for parents' initial interviews ('parents as applicants'), one for carers, one for follow-up interviews with parents using the service ('the consumer sample') and one for parents who remained 'unmatched'. The last group requires some clarification, since it encompasses two separate samples. As explained in the preceding discussion, it was not originally intended to interview parents who withdrew from the scheme, but in the course of interviewing those on the waiting-list, it became clear that some did in fact consider their application closed. Meanwhile, two other families had withdrawn from the scheme, having made some use of it. The phenomenon of withdrawals was thus identified as a significant factor which required closer examination. By this time, however, the questionnaire originally designed for those who remained on the waiting-list had already been used with two families who now fell into the new sample. Not surprisingly, some of its questions had proved inappropriate, while others had been expanded with supplementary ones. It was therefore decided to continue using the same questionnaire, adapted as necessary during interviews with families who withdrew.

However, this schedule was clearly quite unsuited to those parents who withdrew after having made some use of the scheme, however limited. A fifth schedule was therefore devised. As the

numbers concerned were very small, yet the circumstances surrounding breakdown might vary considerably, this questionnaire was considerably broader and more open-ended than the others. Care was taken, however, to ensure that all appropriate questions were answered in each interview. A questionnaire with a similar format was designed for use with carers who had been linked to these families.

Pilot Interviews

The purpose of conducting pilot interviews is to test the format of the questionnaire for validity and reliability. Stacey (1969) mentions another useful purpose - to check the length of the schedule. She suggests that a compromise may be required between the depth and range of material which the researcher would like to gather and the limitations of time and resources. To these considerations might be added the amount of time the researcher can reasonably expect her respondents willing and able to allocate to the interviews.

The questionnaire designed for initial interviews with parents was piloted with two parents already using the scheme. As the bulk of these questions refer to aspects of bringing up the child and family life, the fact that these people were already using the service was not considered problematic although the final section, dealing with their application to the scheme, had to be answered retrospectively. Following these interviews (and with the benefit of parents' comments on the questionnaire), four main changes were made. Firstly, some questions were clearly repetitive. These were either omitted or condensed into a single item. Secondly, the wording of others was changed, to make them clearer and/or more precise.

Thirdly, a couple of additional questions were added to introduce a neglected area (for example, about the financial effects of caring). Lastly, it was interesting to find that despite my efforts to avoid making the questionnaire sound 'negative', one respondent expressed reservations. She commented:

Life isn't horrific, and I sometimes think these forms are looking for horrors that aren't there.

A couple of questions were accordingly omitted.

Similarly, the carers' schedule was pre-tested with two well-established carers. This time the questionnaire (containing 148 questions) proved much too long; again, several repetitive items were condensed or omitted. Some had included attitudinal scales, which proved inappropriate for the highly qualitative nature of the responses. These were also dropped from the final version, leaving the questions more open-ended.

The two questionnaires designed for follow-up interviews with parents were also pre-tested with respondents in similar situations. These required fewer amendments, perhaps because, by that stage, I was more familiar with the substantive issues of the research and with methods of questionnaire design.

Making Contact

Once the samples had been identified and the questionnaires finalised, an introductory letter was sent out to potential respondents from the Scheme Co-ordinator. This briefly outlined the nature and purpose of the research, ensuring recipients that while their participation would be greatly appreciated, it was entirely voluntary. It also stressed the confidential nature of the study. Finally, the letter stated that I would contact parents by telephone

the following week to ascertain whether they were willing to be interviewed. Although it is common for researchers to ask potential respondents to complete a tear-off slip, indicating their willingness, or otherwise, to take part, it was thought that direct telephone contact, following an introductory letter, might be a more efficient means of gaining a higher rate of positive responses. This approach proved successful, yielding an overall response rate of almost 95%, higher than average for family research (Hill, 1984). Respondents' willingness to be interviewed was probably related to their close involvement and interest in the subject-matter of the study.

Conducting the Interviews

Both parents were asked to attend the interview if possible, but in practice this objective was not consistently achieved. Initial interviews, for example, were conducted with 14 couples, 1 father and 15 mothers, five of whom were single parents. Some fathers were unable to attend because they were working, but in other cases it appeared their absence was more voluntary. Both 'childcare' and 'talking to professionals' were apparently seen as the wives' concern rather than the husbands'. Efforts to include both partners were more successful in relation to carers. 21 couples took part, while nine wives were interviewed alone. Three single carers also participated.

In retrospect, a mistake was made in failing to find a way of including both carers' children and the handicapped child's siblings. Macaskill (1985), in a study of adoptive families of children with handicaps, devised a 'Family Fun Sheet' for use with younger natural children, and asked older ones a number of questions. Some items in

the present study did relate to these family members, but were generally answered by parents, although if children were present their views were also sought. Unfortunately, it was not possible to involve the children with handicaps; the majority did not have high levels of comprehension, and almost half had little or no speech. 7

The interviews were all tape-recorded, unless respondents chose otherwise, as did four parents and one carer. Interestingly enough, all the parents who preferred not to be recorded later withdrew from the scheme, suggesting this may have been an early indication of a wider reticence. A further three interviews were not recorded successfully due to mechanical failure (or human error). Lofland (1984) recommends that taking 'sparse notes' should accompany the use of a tape-recorder, in order to help the interviewer identify those subjects which have been fully covered and those which remain to be raised. Note-taking should not be allowed to distract the interviewer from careful listening nor from reassuring the respondent that he is being listened to. ✓

As discussed earlier, it was intended that the interviews would yield data on a large number of specific questions and to some extent the conversation had to be guided in such a way as to cover all the points raised in the questionnaire. At the same time, however, the interviews were conducted in a flexible manner, a considerable amount of informal discussion taking place. While this held varying degrees of relevance to the subject-matter of the research, it served a crucial role in 'breaking ice', establishing rapport and paving the way for later discussion. Equally, it allowed respondents to develop their own frame of reference and to highlight issues which might have received scant attention had the questionnaire been administered in a

more structured way. As Lofland (1984) points out, some respondents are more forthcoming than others, who may be less spontaneous in developing (or articulating) ideas. Perhaps partly as a result of this variation, initial interviews with parents and those with carers lasted between one and two and a half hours. Follow-up interviews tended to be shorter, from one to one and three quarter hours.

I have already discussed issues related to the presentation of self during interviews. These points will not be repeated here, other than noting that the researcher attempted to communicate empathy with, interest in and uncritical acceptance of respondents' accounts. Some interviews had a better 'feel' to them than others, in terms of both rapport and the quality of data obtained, although the vast majority seemed reasonably successful in both aspects. One which was not was completely discounted from the sample. It may be worth noting that those interviews in which I felt most aware of my role as researcher were probably less successful than those which appeared to be conducted on a more equitable basis. During the initial interviews, it was important to learn to distinguish between the roles of researcher (my current identity) and social worker (my previous identity). Jenkins (1975) offers a useful discussion on this point.

Supplementary Data Collection

Early in 1984, I began to collect data from agency records, mainly in the form of note-taking, for example about recruitment campaigns, the Share-the-Care Pilot Project and carers' preparation groups. However, as previously explained, the amount of comprehensive information available on the scheme's operation was limited. Special forms were devised for collecting information about

the personal and social characteristics of parents and carers (in relation to the latter, for example, this covered their marital and occupational status, date-of-birth, type and tenure of dwelling, family composition and so on). Gaps in agency records were supplemented whenever possible by seeking information from social workers. The forms were pre-coded and data fed onto the computer. A postal questionnaire was designed for professionals who had made referrals to the scheme. For reasons already discussed, this included several open-ended questions and focused on respondents' perceptions of the scheme and their contacts with both families and carers involved in the service. 34 questionnaires were sent to area teams, hospitals, schools and a voluntary organisation. 22 were returned.

Analysis

As Lofland (1984) has pointed out, full literal transcripts of tape-recordings can be made by a researcher who is 'affluent, or has extraordinarily indulgent associates'. In this case, however, limited resources confined recording to part-transcripts, made as soon as possible after each interview. A separate questionnaire had been used for each interview and the notes taken then were now amplified into fuller answers for every question. Where respondents had provided extensive information on a topic, this was noted on additional sheets of paper. Word-for-word transcripts were made of data which appeared to carry particular significance for either the individual respondent or the study as a whole; some issues, through repeated appearance, were beginning to assume theoretical or substantive importance. Additional brief notes were also made, where appropriate, regarding the 'mood' or 'affect' of the interview, which

sometimes helped to place the data into sharper perspective.

The activity of listening to each tape-recording is an important first step towards analysis, not only because material is selected or discarded for transcribing purposes, but also because the researcher begins to formulate ideas and speculate about possible relationships between variables (Lofland). As certain issues emerged which seemed particularly significant, these could be pursued in greater detail during subsequent interviews.

Throughout the study, a series of diaries or notebooks were kept. Lofland has suggested that at least three different kinds of 'file' should be instituted, which he calls 'mundane', 'analytic' and 'fieldwork'. In this study, however, a single diary was used for notes on various aspects of the research - observations made within the agency, ideas for questionnaire design, and early attempts at analysis. These notebooks also served as more personal diaries, in which the frustrations, anxieties and excitement of the research process were recorded. ✓

However, a more formal process of analysis began before the fieldwork was finished. The first step was to make a photocopy of each questionnaire which was then, literally, cut up according to individual questions. Each collection of 30 answers to individual items was 'filed' in separate, labelled envelopes. Each set of responses was then examined; those which were identical or similar in content being grouped together under a single category. As the total number of cases was small, the number of categories was also kept small and therefore fairly broad. At the same time, Lofland's recommendation that categories should be exhaustive and mutually exclusive was implemented. The procedure may best be illustrated

with an example. Carers had been asked if they were aware of any significant differences in lifestyle between themselves and the family to whom they were linked. Six categories were devised to cover all the responses, namely:

- None
- Leisure activities and/or environment (rural/urban)
- Family composition
- Domestic routine
- Social background
- Other

On the advice of colleagues, it was decided to use SPSS(X) (the Statistical Package for the Social Sciences created at Stanford University) to analyse the data on the computer. For this purpose, variables were labelled and categories numerically coded. Although the majority of categories were nominal, as above, ordinal, ratio and interval measurements were also used, largely for ease of transfer onto the computer. The limitations of this treatment of qualitative data soon became clear, as will shortly be explained. The same procedures were applied to data obtained from agency records regarding the social and personal characteristics of scheme users. Smith and Reid (1981) comment on the importance of defining categories as clearly as possible, in order to enhance reliability. For this purpose, a 'coding book' was used, which listed in detail:

- the original question put to respondents
- the variable label created for the computer
- the categories created, along with their numerical codes
- classification of any categories which might otherwise appear unclear.

Using SPSS(X) it was possible to produce frequency tables and cross tabulations, to which a chi-square test of association was then applied. Fisher's exact test is used for two-way tables of less than 20 cases; otherwise, SPSS(X) applies Yate's corrected chi for small samples. Results of this test are usually considered significant at the 0.05 level. Despite these safeguards, however, nearly all the tables produced by the system contained a large number of cells with an expected frequency below 5. Since the validity of such results is open to question, it became clear that great caution would need to be exercised in 'interpretation'. Robson (1973) comments:

Although statisticians differ on the exact number below which χ^2 should not be used, a simple rule of thumb is: Do not use chi-square if one or more of the expected frequencies falls below five.
(p.88)

As this guideline coincided with advice received from statisticians, initial attempts to apply chi-squared testing on a broad basis were abandoned. The possibility of creating more two-way tables, and of employing alternative methods of statistical testing were briefly considered but soon discounted, for a number of reasons which I shall shortly outline. With such small samples, similar caution must be exercised in the use of percentages and fractions.

The computer served a useful purpose in analysing straightforward factual data. For example, it produced useful numerical information concerning carers' previous experience in childcare, voluntary work and contacts with people with mental handicaps. It provided a quick and efficient means of identifying unusually high or low frequencies, uneven distributions or unexpected clusters. It did not, however, allow for any more detailed, in-depth exploration of relationships between variables, nor the real meanings

behind the unexpected cluster. It became increasingly clear that while coding data in terms of separate, individual items had been a useful exercise for initial analysis, this now had to be developed by means of a more qualitative approach. Although the sample was small, many questions had been open-ended, yielding rich data about complex feelings, attitudes and perceptions. That richness and complexity had been lost through the rigid coding procedures required for computer analysis. Often the answers to individual questions acquired a deeper, or even a different, meaning when set alongside data obtained, during the same interview, in response to other questions, or which had arisen spontaneously in the course of discussion, a process also noted by Fisher, Marsh and Philips (1986). Greater attention must now be paid to the **meaning** of each answer, and to the theoretical implications of the data, rather than the number of times a similar response had been articulated. I returned to the tape-recordings of parents' initial interviews, this time noting down data specifically related to stress and coping strategies, definitions parents made of their situations, attitudes towards sharing care in general and Share-the-Care specifically (in relation to their application). This time, data was not separated and grouped according to individual items on the questionnaire, but under key themes (such as 'stress' and 'coping'). This allowed for the emergence of what McGlew (1983) calls the 'complex connectedness' between variables, the identification of other concepts (such as 'positive perceptions') and the emergence of patterns within and between individual cases. It also highlighted areas of differences between some.

Lazarsfeld (1985) suggests that the interaction of thought and

analysis creates 'imagery' by which he means that the analyst begins to form images and constructs. She realises that seemingly unconnected factors do in fact share some underlying unity of meaning. At the same time, the researcher must keep in mind the aims of her study - by this stage, the phenomenon of different outcomes in service utilisation had emerged as a significant factor which required closer examination, while the original objective of assessing the scheme's effectiveness in reducing stress remained an important priority. It became increasingly obvious that families differed greatly in their definition of their situations, the meanings they gave to parenting a handicapped child, and their perceptions of the effects of caring on other aspects of family life. Most importantly, these perceptions were not necessarily related to factors which could be objectively tested, nor numerically counted. For example, it emerged that parents' satisfaction with their social life was not linked to frequency of social outings together. Rather, it related to the meanings ascribed to their social life in relation to meanings ascribed to other aspects of their lives. Thus, one couple, who went out together about once in three months, was relatively satisfied with this situation because they accepted a restricted social life as inevitable for parents of young children. By perceiving it as something they had actively chosen, or at least undertaken consciously, they were able to feel in control. Furthermore, by seeing it as a 'normal' part of parenthood, they were able to maintain a positive perception of this aspect of caring for their handicapped child. Another couple, however, who went out regularly once a week, felt very dissatisfied and attributed the cause of their frustration to the fact that their young son had a

handicap which created difficulties in finding suitable babysitters. A third couple, who went out once a fortnight, was also dissatisfied but perceived the problem differently again. A babysitter was available, but they could not afford to go out more often. All three couples had a child aged under five who was profoundly handicapped. Thus, the pattern emerged of some families holding positive perceptions as an active coping strategy, consistently defining their situation in optimistic terms; others did identify certain areas of difficulty (such as ill-health or marital problems), but tended to be very closely attached to their child and reluctant to make a link between stress and caring. Finally, some families appeared more pessimistic about their overall situation, identifying many areas of difficulty in their lives which they tended to relate to the task of caring. Most viewed this in decidedly negative terms.

Ten variables were selected which related to the stresses and satisfactions respondents perceived in their lives. (These are listed in the following chapter.) Each case was examined and assigned to one of three groups, labelled 'low', 'intermediate' and 'high perceived stress'. The coding of each case for all 11 variables was independently assessed by an interjudge from the field of health and behavioural change who also allocated families to one of the three groups. Her judgements resulted in the transfer of two cases to a different group. At the same time, it was considered most important not to lose sight of the quantitative aspects of analysis. Silverman (1985) has written:

The point, then, is to count the countables, preferably in terms of the categories actually used by the participants ... simple methods of counting can deepen and extend qualitative analysis of linguistically-structured realities.
(p.154)

The new variable - level of perceived stress - was introduced to the computer program and its relationship to other variables explored, within the limitations imposed by the small sample sizes.

At first, an attempt was made to group carers into three distinct categories according to their motivation/orientation towards the scheme and to analyse the rest of the data in terms of this independent variable. However, it was later decided that this exercise had resulted in distortion of data and that, while some distinctions did exist between carers, these were not as clear-cut as had initially been supposed. This line of analysis was therefore abandoned.

Data from the follow-up interviews with parents was not placed on the computer because the samples were too small (being 15, 8 and 4). However, analysis was conducted along similar lines to those described above. Photocopies of questionnaires were dissected and sorted into separate items; categories created and frequencies noted down. This exercise served both as a useful springboard for more qualitative analysis and as a constant reference point. Attention then focused on the identification of key themes, exploration of relationships between variables and examination of emerging patterns, similar to the method described above. The process of writing up findings from second interviews began at an earlier stage this time and was more closely related to analysis. Indeed, the activity of writing seemed to lend greater structure, focus and impetus to analysis. This style is, apparently, typical of 'steady plodders' (Lofland, 1984), that is:

people who write a little each day, methodically and laboriously building up their analysis (no matter in what order they work out their general design). In this style, one ekes it out slowly, writing and analysing in detail as one goes along.
(p.140)

Qualitative studies have been criticised for a tendency to selectively present data which support their findings. Efforts were therefore made to include some deviant cases in the presentation. When a first draft was eventually completed, it became necessary to gain more sense of the study as a whole, rather than its individual chapters. At this stage, decisions have to be made regarding the omission, expansion, alteration and restructuring of various sections. A balance must be gained between verbatim quotations and numerical tables. Analysis and speculation should not be outweighed by descriptive passages. The final task was to rewrite the initial draft with the aim of achieving a more coherent and, given its original length, a more concise final version. ✓

Evaluation of Methodology

In retrospect, the aspect of methodology which proved least successful was a disproportionate emphasis, during the early stages of analysis, on a quantitative approach. As already noted, the computer served as a useful tool for initial analysis of the two larger samples and simple counting procedures made an important contribution throughout. However, a considerable amount of time was spent in exploring the use of statistical testing which subsequently proved inappropriate. ✓

Secondly, had it been possible to predict the extent of differing outcomes to initial applications (i.e. that nine families would withdraw from the scheme, while five others remained on the waiting-list for many months), the questionnaires for parents' follow-up interviews could have included a more narrative component. This might have precluded the need to design additional schedules in reaction to events. Indeed, it might be argued that all the

questionnaires could have included a greater number of open-ended questions and fewer structured ones. Such a design might have facilitated the process of viewing data as a whole and thus grasping the richness and depth of meaning, rather than seeing individual responses in isolation. Thirdly, the study would have benefitted from the inclusion of two additional samples - the handicapped child's siblings and the carer's children. Information about them was sought, in both cases, from their parents and data thus obtained indicates scope for further enquiry. In retrospect, however, it would have been preferable to find a way of involving these family members directly, had time permitted. Finally, although it was intended to use a triangulated approach, limitations of time and resources meant that, in reality, semi-structured interviews formed the bulk of data collection, while other methods could only be employed to a limited extent.

Summary and Conclusions

In summary, the main aims of this study are to evaluate the effectiveness and quality of the Share-the-Care Scheme and to assess its impact on the lives of carers, parents and children. It therefore requires a theoretical framework capable of addressing the nature of both subjective perceptions and external structures and which recognises the validity of each and co-existence of both. Thus, it was decided to use a triangulated approach to data collection and analysis, with the main emphasis on qualitative aspects. In practice, limitations of time and resources meant that the use of semi-structured interviews dominated research methods, although supplemented to some extent by data from other sources. Analysis was conducted on two levels. One, using the computer, was

necessarily quantitative in style, while the other, involving an in-depth exploration of respondents' meanings and perceptions, was highly qualitative. The latter proved the more fruitful approach, but elements of both are combined in the final presentation of results.

PART II

CHAPTER 4

Parents as Applicants

Introduction

The theoretical framework for the study outlined in Chapter 2 indicated that, while all families experience some degree of stress as they attempt to perform their various functions, the presence of a child with disabilities is likely to act as an additional stressor by imposing certain demands on the family unit. The 'stress' engendered in this process may, at low levels, act as a positive catalyst for adaptive change; at higher levels, it is likely to become more disabling. In their attempts to develop effective coping strategies, families seek to mobilise internal resources, such as their perceptions and definitions of the situation. They may also call on external support, such as a family-based respite care scheme. It was also noted that families differ in their levels of stress, coping styles and attitudes towards shared care.

The purpose of this chapter, then, is to analyse the data obtained from the 30 initial interviews with parents in terms of the perceived impact of caring on family life, the types of support already available and the levels of stress experienced by families. As a considerable amount of data was collected on these subjects, it will be necessary to present much of it in summary form. Finally, parental expectations of Share the Care will be examined. At this stage, only one child had stayed overnight at his carers. A few families had been introduced to potential carers, while others were still awaiting acknowledgement from the Scheme that their application had been received.

The chapter begins, however, by examining the sample's personal and social characteristics and circumstances. This information was obtained from agency records, supplemented where necessary by interview data or through discussion with social workers.

Personal and Social Characteristics of the Sample

(i) Socio-economic Status

As Table 4.1 illustrates, the sample was equally divided between families from 'manual' and 'non-manual' occupational categories, as classified by the Registrar-General (1980). Families were assessed according to the father's occupation simply because 25 mothers were not working and a further four were employed for only a few hours per week. Single mothers, however, are classified by their last occupation, as are four unemployed men, one senior citizen and one postgraduate student.

TABLE 4.1 Occupational Status of Families

Occupational Status	Number of Families
Non-manual	15
Manual	15
Total	30

These figures are comparable to those for the male working population in Britain in 1983, when 44% were employed in non-manual occupations and 56% in manual (Employment Gazette, 1985).

Table 4.2 demonstrates tenure of dwelling, again suggesting a fairly even divide among the sample.

TABLE 4.2 Tenure of Dwelling Among Families

Tenure	Number of Families
Owner-occupied	14
Local authority	14
Privately rent/tied	2
<hr/>	
Total	30

The figure of nearly 47% for owner-occupancy is higher than that for Scotland in 1983, which was 36% (Office of Population Censuses, 1983).

However, when the sample was examined in terms of social disadvantage, a rather different picture emerged. Where two of the following four factors were present - long-term unemployment, financial hardship, poor housing and social isolation - families were classified as 'socially disadvantaged'. Nine families fell into this group - almost a third of the sample. The unemployment rate among fathers was 16%, compared to 19.5% among men in Scotland in January 1985 (Employment Gazette, 1985). Among mothers, it was 83.3%, massively higher than the official figure of 11.5% for women in Scotland, even allowing for the fact that many married women do not register. The overall unemployment rate in Lothian at that time was 12.7% (Employment Gazette, 1985). These figures can also be compared with those provided by Robinson (1986) concerning 104 families using the Avon Family Support Service. She reports an unemployment rate among fathers similar to the national average for men, but much higher for women. A number of mothers in both samples reported difficulties in obtaining and/or managing a job due to the demands of caring, a factor commonly reported elsewhere (Bradshaw and Lawton, 1978; Baldwin, 1976; Glendinning, 1983).

(ii) **District**

Fifteen families lived in the city of Edinburgh, nine in West Lothian and six in Midlothian. It is striking that no new referrals were received from East Lothian during the fieldwork period. The slow development of the scheme in that division is discussed in Chapter 9.

(iii) **Age, Sex and Family Composition**

Although 30 families were interviewed, one couple had applied to the scheme for two children. The sample therefore contains 31 children, 16 boys and 15 girls, ranging in age from 15 months to 14 years at the time of application, their average age being just over 8½. The average age of the Avon sample was 10½. The difference can be explained by the fact that the Avon scheme caters for 0-19 year olds.

Twenty-one children were living with both natural parents. The finding that one in three was not doing so is strikingly higher than that of Osborn, Butler and Morris (1984), who found that one in ten 5 year olds was not living with both natural parents. Whether or not this difference is linked to the presence of a handicapped child is unclear: as already discussed, evidence about the effects of caring on marital relationships is conflicting. The higher incidence of separation in this sample may be partially explained by the older average age of the children involved. Four were now living in reconstituted families (including two cohabiting couples), while two had long-term foster parents (one of whom was single). There were altogether five single parents, representing 16.6% of the sample, compared to a national average of 13% for the years 1982-84 (Office of Population Censuses, 1984).

Table 4.3 indicates the number of children (including adult offspring) in each family, while Table 4.4 indicates the handicapped child's position in the family.

TABLE 4.3 Number of Children Per Family

No. of children	Number of families
1	8
2	12
3	5
4	3
5	2
Total	30

TABLE 4.4 The Handicapped Child's Position in the Family

Child's position in family	Frequency
Only child	8
Oldest child (including twin)	7
Middle child (second or third)	3
Youngest child	13
Total	31

The sample had an average of 2.3 children each, very close to the Avon average of 2.4 but higher than the national figure of 1.8 children per family in 1984 (Office of Population Censuses, 1984).

(iv) **Schools**

At the time of application, four of the 31 children were not yet at any school. A further two attended nursery school and another went to a children's centre. The rest were all pupils at special schools in the Region.

(v) **The Children's Abilities and Self-help Skills**

In Chapter 2 it was noted that some studies have related a high incidence of family stress to certain characteristics within the child, and the care demands arising from these. Particular aspects which have been identified include multiple handicaps and ill-health (Pahl and Quine, 1985), feeding difficulties and a low level of self-help skills (Carr, 1975), the need for constant supervision (Glendinning, 1983) and the child's age and severity of handicap (Wilkin, 1979). On the other hand, a number of studies have discounted any direct link between the two (Bradshaw and Lawton, 1978; Kendall, 1982).

Table 4.5 shows the children's range of self-help skills. Most were able to feed themselves, but few could wash, dress or use the toilet without assistance, and in each area over a third of the sample required these tasks to be done for them.

TABLE 4.5 Children's self-help skills

Level of Ability	Feeding	Dressing	Washing	Toileting
Fully able	22	5	5	9
Needs help	2	15	14	5
Quite unable	7	11	12	17
Total	31	31	31	31

Parents
info

Infir.
Child.

Many of the children were restricted in terms of mobility, speech and/or continence (see Table 4.6). Of the 31, ten were either non-ambulant or could only crawl, 13 had very little or no speech and 17 were doubly incontinent.

TABLE 4.6 Children's abilities

Level of ability	Area of ability		
	Mobility	Speech	Continence
Few or no problems	17	11	9
Limited ability	4	7	5
Very limited or none	10	13	17
Total	31	31	31

Eleven children had severe physical handicaps, that is, they had a disability which greatly restricted or interfered with their daily activities, such as deafness, blindness or paralysis. Six also suffered from a serious medical condition, while a further nine had problems such as allergies or asthma. Only one child was said to have no intellectual handicap. Table 4.7 outlines the diagnoses which had been made of their conditions.

TABLE 4.7 Diagnoses of children's conditions

Diagnosis	Number of children
Cerebral palsy/hydrocephaly	7
Downs syndrome	6
Non-specific brain damage	5
Rare syndromes	3
Autism	3
No diagnosis	7
Total	31

In conclusion, although the children spanned a wide range of abilities, as a group they did have severe disabilities and 11 could be described as profoundly and/multiply handicapped, representing a third of the sample.

Again these findings are comparable to those reported by Robinson in relation to children using the Avon Family Support Service. Although that scheme also accommodates children with widely differing handicaps and abilities, the majority have a severe mental handicap while just over a third have a severe physical handicap.

(vi) **Child's Behaviour**

Several studies have shown that the levels of stress experienced by families is related to the management problem presented by the child (Wilkin, 1979; Chetwynd, 1985; Pahl and Quine, 1985). However, it has also been found that perceptions of behaviour differ markedly between observers, (Jeffree, Cheseldine and Shorron, 1981; Martindale, 1982) and that individuals display different kinds of behaviour according to their environment and in response to the actions and interpretations of others (Bronfenbrenner, 1979; Sutton, 1985).

The quality of information contained in agency records regarding the nature of children's behaviour proved to be very inconsistent. In some cases brief and highly generalised accounts were given; in others, subjective and sometimes conflicting impressions from a variety of sources were recorded. I will therefore present the perceptions of parents, as obtained during the interviews, not because these are likely to be any more 'objective' than others but, firstly, because this data represents a comparable amount of information collected in all 30 cases in response to the same or

or similar set of questions and, secondly, because parental perceptions are the primary concern of this chapter.

Parents differed greatly in their accounts of the children's behaviour. In 11 cases, few or no difficulties were reported; moderate problems emerged in eight cases while 11 parents reported severe difficulties. As might be expected from the evidence of the studies quoted above, parents' assessments of the degree of difficulty presented by their child did not always appear to correspond to the actual behaviour described. Thus, one girl's tendency to throw tantrums was seen as constituting 'few or no problems' by her family while dressing inappropriately for the weather was cited as an example of the severe difficulties posed by another child. Clearly, parental perceptions of children's behaviour was related to a range of mediating factors including the broader meanings they gave to parenting a handicapped child. Similarly it seemed that parents who could identify a reason for a particular behaviour, (for example, the ability to view a child's compulsive eating as an inevitable part of his particular syndrome) were more able to tolerate it, whereas those who could find no satisfactory explanation, except perhaps deliberate provocation on the child's part, perceived it as more problematic.

However, it would be wrong to underestimate the very real problems faced by a number of parents. One mother, for example, gave the following account of behaviour recently exhibited by her 6 year old son:

More data expected here

For three months solid he just screamed day and night and we couldnae do anything for him. He wasnae wanting us to help him at all. And he was biting hisself, he'd big chunks out of the back of his hands and his knees and he was throwing hisself about ... for 3 months that went on ... it frightened the life out of me ... the only person who came near me was my mum and she was getting as much as what - I mean we were getting bitten and scraped and everything as well ...

In this case, as in several others, parents' desperate need for relief from their children's difficult behaviour was the principal reason for their application to Share-the-Care. h

(vii) **Representativeness of Sample**

Overall, this sample appears strikingly similar to that using the Avon Family Support Service. However, it was also thought useful to explore its representativeness of the wider population. For this purpose it was compared to Hunter's sample (1980) of 149 families with severely mentally handicapped children, aged 0-16, living in West Lothian and Lanarkshire. Since these families were contacted through local education, health and social work departments and a voluntary agency, they represent a wide cross-section. It emerged that among the present sample there was a considerably greater number of single parents (16.6% as opposed to 9.5%) and a higher proportion of only children. Overall, then, the families are markedly smaller. Hunter's sample had a higher proportion of fathers employed in unskilled labour and a smaller proportion out of work. The former difference is probably related to geographical location, the latter to rising levels of unemployment during the 1980s. The employment pattern among mothers, however, was very similar. With regard to the children themselves, just over half of Hunter's sample (79 out of 149) were severely mentally handicapped with at least one other

physical disability while just under half of the present sample fell into that category (14 out of 31) indicating great similarity. Forty-two of Hunter's sample were taking medication, less than a third, as opposed to 13, almost half, in the present sample. In both cases medication was mainly for epilepsy or hyperactivity. This brief comparison appears to indicate that the present sample is reasonably representative of the wider population, at least in terms of social and demographic characteristics.

(viii) **Summary**

In summary, the present sample consists of 16 boys and 15 girls, ranging in age from 18 months to 14 years, with an average of 8½. The majority have severe disabilities, over a third being profoundly and/or multiply handicapped. Their parents were divided equally between manual and non-manual occupational categories, although almost a third were currently unemployed. Five were single parents and nine families might be classified as socially disadvantaged. It is worth noting that the only obvious common factor shared by all the families was that of having a handicapped child, resulting in their application to Share-the-Care.

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Tables

I will now move on to analyse the data obtained from initial interviews. To a large extent this will be a narrative account, summarising material, with the aim of exploring the perceived impact of caring on, and its interaction with, other aspects of family life.

Perceived Impact of Caring on Family Life

(i) **Division of Labour**

The high degree of dependency among many children clearly necessitated a considerable amount of physical care. Role flexibility and sharing tasks can reduce stress and enhance coping

strategies (Pratt, 1976; Venters, 1981). At the beginning of the interviews, parents were asked to identify, in relation to nine practical aspects of caring for the handicapped child, firstly, whether one person was solely or mainly responsible for each task, secondly, whether anyone lent a hand or, thirdly, whether it was equally shared. This framework was borrowed from Wilkin (1979), who found that parents related easily to these distinctions. It was hoped that by naming specific tasks and differing levels of responsibility, findings would reflect the division of labour as accurately as possible. The same questions were posed in relation to six domestic chores, such as cooking, shopping and household repairs (see the Appendix).

The principal finding to emerge is the huge responsibility carried by most mothers for both childcare and housework. Twenty-eight mothers had sole or main responsibility for washing clothes, 29 for making practical arrangements concerning the child, for cooking and cleaning, 19 for dressing the child and 18 for washing him. More fathers than mothers carried the main responsibility for providing transport (N=11) and for household repairs (N=15). Tasks more likely to be shared by partners were dealing with sleep disturbance and general supervision, while activities in which children participated were dish-washing and playing with the handicapped child. Siblings, however, made a minimal contribution overall. These findings are similar to those of other studies, including several unrelated to handicap (Bayley, 1973; Oakley, 1974; Weale and Bradshaw, 1980). Osborn, Butler and Morris (1984) report that 38% of 13,315 mothers received no help with shopping and housework.

These findings suggest that the presence of a handicapped child does not alter the traditional division of labour within the family, although the fact that most mothers were not employed outside the home may have encouraged minimal sharing of domestic and childcare tasks. It is important to note, however, that many were fully occupied during the day while their children were at school, in tasks associated with caring, such as washing soiled sheets or clearing up after a hyperactive child. Comments on the exhausting nature of their role and the 'hard work' it entailed, were frequent.

(ii) **Daily Routines**

Despite the need for a high level of physical care in many cases, families varied considerably in the extent to which their daily routines were shaped by the demands imposed by the child. Some parents were careful not to allow the child's needs to supersede those of other family members. They commented:

We base our routines around the family unit - Jenny
isn't singled out

and again

Paul fits in with what I have to do and what the
family is doing

Other parents, however, reported a degree of restriction on their movements and activities. Sometimes this was because the child's behaviour was unpredictable and could cause embarrassment in public places. Several children were prone to serious epileptic fits. Some required a number of aids and special equipment if they went out anywhere, which could pose considerable practical and logistical problems.

Nineteen children were described as requiring almost constant supervision, which many parents found very wearing. The need to be continually aware of the child's activities and whereabouts left parents little opportunity to relax.

About a third of the sample reported that their lives revolved totally around the handicapped child. In some cases this was presented as an effective coping strategy - the best way to deal with a demanding situation. In others, parents expressed considerable dissatisfaction with what they perceived as an imbalance in family life, giving rise to problems in other areas. One father commented:

It is a lot of stress looking after a handicapped child, a lot of hard work. Family routine is interrupted. It causes a lot of other difficulties - I can't give my older son the attention he needs.

Another father remarked:

It affects the grassroots of family, the problem.

Few couples had the opportunity to spend much time together, without their children, during the average week. This is probably true of most parents of young children and, indeed, those who viewed such restrictions as a normal part of parenthood were more able to accept them:

We're quite happy. We never really thought about it. You just look after the kids as long as they're up, and then, the rest of the time's yours really.

Other parents, especially those whose children had disturbed sleeping patterns or difficult behaviour, encountered greater problems. One mother, for example, whose son demanded full-time attention during the day, had to wait until his bedtime if she

wanted to have a reasonable conversation with her husband. By that time, however, she was usually 'too tired to think'.

If anything, parents seemed to feel more strongly about the lack of time they had to themselves as individuals, although several commented that they made the most of what little free time they did have.

(iii) Social Life

Parents were asked how frequently they went out in the evenings socially (together, if a couple) and how satisfied they were with this. As Table 4.8 indicates, frequency of nights out did not necessarily correspond to levels of satisfaction. Again, it emerged that the meaning given to social life and the causal explanations invoked for its frequency were more significant in determining overall satisfaction than was frequency itself (this point has already been discussed in some detail in Chapter 3, in relation to assessing levels of stress). Nevertheless, it is striking that half the sample went out (together) only once in three months or less, although some fathers made more regular visits to a local pub.

TABLE 4.8 Crosstabulation : Frequency of Social Nights Out and Reported Satisfaction

Frequency	Levels of Satisfaction			Total
	Satisfied	Mixed feelings	Dissatisfied	
Frequent (once in 1-2 weeks)	3	1	4	8
Average (once a month)	2	2	2	6
Infrequent (once in 3 months or less)	8	2	6	16
Total	13	5	12	30

These findings are similar to those of other studies which indicate that, while some families may be restricted in their social lives, certain mediating factors also play a part. Hewett (1970), for example, suggests that feelings of loneliness were related to mothers' personalities. Carr (1975), on the other hand, reports that as many as 75% of mothers in both her samples were satisfied with the frequency of social evenings spent outside the home, while half of Kendall's respondents (1982) encountered no difficulty in going out together as a couple.

(iv) **Holidays**

The availability of a holiday can reduce stress and enhance coping, particularly if it involves respite from the demands of caring (Chetwynd, 1985). However, families with handicapped children may experience difficulty in fulfilling their recreational functions, including organising holidays (Turnbull et al. 1984). This did not apply to 17 families in the present sample, who had taken a holiday during the twelve months prior to interview. These holidays usually included the handicapped child and lasted, on average, just under a fortnight. Six families had taken no holiday for two years and seven not for considerably longer. In only two cases was this said to be related to difficulties posed by the child; in others, financial hardship was the main obstacle cited. On the other hand, several parents hoped that joining Share the Care would afford them greater opportunity to go away without the child.

(v) **Marital Relationships**

Three parents are excluded from this section: a widow, a woman who had fostered a handicapped child some time after separating from her husband and a single parent of several years' standing.

The inconsistent and sometimes conflicting nature of research findings concerning the 'effects' of caring on the marital relationship have already been discussed. It was also suggested, using the transactional model, that the child's presence is unlikely to have any single nor inevitable type of effect but will interact with other variables within the individual situation to produce differing results in each family. Table 4.9 illustrates this kind of variation among the present sample, although the coding categories can only give broad indications of the raw data.

TABLE 4.9 Parental Perceptions of the Effects of Caring on Marital Relationships

Type of Effect	Number of Cases
Mostly negative	14
Mostly positive	6
No effects	4
Mixed effects	3
N/A	3
Total	30

Make more of.

It has been suggested that family relationships can be utilised as a positive resource within an effective coping strategy (Folkman, Schaefer and Lazarus, 1979), and some evidence of this process was found among certain families. One mother, for example, who perceived her son's presence as having a beneficial effect on her marriage, referred to improved communication with her husband:

It might have made us closer. It might have made us talk more than we might otherwise do, about his schooling, say.

Turnbull et al (1984) argue that the expressive functions of families, and particularly the affectional, should receive greater attention. They point out that the presence of a handicapped child in the family may foster a sense of belonging and cohesion. One father commented:

Och, we ha'e oor arguments an' that, what couple disnae? But Jack's the pacifier.

On the other hand, however, half the sample did report difficulties within their relationships which they attributed at least partly to the demands of caring. Problems ranged in type and degree from frequent irritability, due to fatigue, to full-scale marital breakdown. One couple commented as follows:

Mother : It strains (our marriage) quite a lot.
We have a lot of arguments. If I think he's being too hard on Tina, I end up raising the roof, and vice versa. Basically, Tina gets me down so much that I get in a right horrid mood and I can be in that mood for quite a while.
Father : That's when I tell her to take a walk.

Aspects of parenting the child which appeared to place most strain on relationships were disagreements over child management, lack of shared leisure time and a low level of sharing childcare tasks and responsibilities. Other couples who were experiencing inter-personal difficulties were reluctant to identify the child's presence as a contributory factor and pointed to other causes, such as unemployment and financial worries or, conversely, pressures of work.

Again, a number of parents expressed the hope that the opportunity of regular respite would have a beneficial effect on their own relationships.

*Worries about
respite*

(vi) **Siblings**

As already discussed in Chapter 2, research on the effects of the handicapped child on her siblings, like that on marriage, has produced largely inconclusive results. Many studies have tended to assume that a pathological rather than therapeutic response takes place, while paying little attention to the quality of the relationships involved (Simeonsson and McHale, 1981). Both aspects were raised in the present study, although a weakness which can be identified in retrospect is that siblings themselves were not interviewed. Data therefore consists of parental perceptions.

Eight of the children in the sample had no siblings. Among the rest, parents reported that most had good relationships with their brothers and sisters. Some children tended to bicker at times, like most young siblings. Many parents emphasised the importance of treating all their children in the same way as far as possible. Nevertheless, over half reported that they felt unable to give sufficient attention to their non-handicapped offspring and believed that the latter were restricted in certain ways as a result of having a disabled sibling. For example, some were unable to pursue certain activities when the handicapped child was present, be it hill-walking or visiting museums, while one or two appeared reluctant to bring home their own friends. On the other hand, most siblings took an active part in playing with the child and several parents believed the experience had fostered caring attitudes and mature personalities among siblings. In one family, for example, two adult daughters had become nurses with people with mental handicap, while a third was involved in related voluntary work. In the majority of cases, then, a mixture of positive and negative points were made. These findings

are similar to those of Carr (1975) who compared 54 families with Downs syndrome children to a matched sample of families with non-handicapped children. She reports that over two-thirds of siblings in each group were 'easy children who gave no real trouble'.

However, in five cases more serious problems were showing up in the non-handicapped children's behaviour, three of whom were of pre-school age and perhaps finding it difficult to understand why a large proportion of their parents' attention must be focussed on an older sibling. Parents described the aggressive and demanding behaviour of these youngsters as a great strain. The most extreme case, however, was that of a 7 year old girl who was obsessively attached to her 4 year old handicapped sibling and who appeared to have adopted the parenting role within the family. She was described by her mother as constituting 'more of a handicap' than her disabled sister. Finally it may be noted that enuresis, commonly associated with stress, was present in four older children.

Several parents identified their need to spend more time with their non-handicapped children as a significant reason for, and/or anticipated benefit of, their application to Share-the-Care.

(vii) Health and Energy

Many studies have shown that mothers of handicapped children suffer poor health, particularly stress-related conditions (McAndrew, 1976; Hunter, 1980) yet others indicate that in this respect they differ little from mothers of non-handicapped children (Hewett, 1970; Carr, 1975; Wishart, Bidder and Gray, 1981). Osburn, Butler and Morris (1984) found high levels of depression and fatigue among 13,315 mothers of 5 year olds, most of whom had no handicaps. Fathers' health has received less attention, apparently due to an

assumption that they will be less affected, although this view has been challenged (McConachie, 1982). Little research has focused on siblings' health. Both were included in the present study.

Tables 4.10 and 4.11 record, in quantitative form, data relating to the physical health and psychological well-being of parents. Classified under the latter heading were feelings of depression, anxiety, exhaustion and similar conditions. Medical ailments which are sometimes described as stress-related, such as backaches, stomach ulcers and Crohn's disease, were nevertheless treated as 'physical', since no proof of association was available in these cases. Decisions about coding both variables, in terms of 'no problems', 'moderate problems' and 'severe problems', were made with the guidance of a psychiatrist.

TABLE 4.10 Physical Health of Parents

	Mothers	Fathers
Few/no problems	14	18
Moderate problems	11	5
Serious problems	5	2
Total	30	25

TABLE 4.11 Psychological Well-being of Parents

	Mothers	Fathers
Few/no problems	13	17
Moderate problems	9	5
Serious problems	8	3
Total	30	25

In line with findings made elsewhere (Wing, 1975), these figures indicate a higher rate of psychological difficulties for mothers than for fathers, over half the former reporting some degree of stress-related disturbance. However, it should be noted that about a third of fathers also fell into this category. and
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While several siblings had experienced the usual childhood illnesses, four had more serious medical complaints and two were seeing a psychologist. The incidence of enuresis among older siblings has already been noted.

Again, attitudes towards health varied considerably across the sample. Some families appeared to use their good health and plentiful energy as an active coping resource, for example, by pursuing friendships and activities outwith the home. They may be seen as corresponding to the 'energised family' identified by Pratt (1976) as 'the most effective structure' for carrying out important functions such as protecting health and developing physical capacities. Others, who may have preferred to focus their energy within the family unit, adopted a more self-sufficient attitude. One father commented:

There have been periods of depression, but nothing major. We can't afford to be seriously ill - who'd keep everything going?

However, some parents were experiencing enormous stress in their day-to-day lives, both created and exacerbated to some extent by poor health, as this single father explained:

Since my operation, my personality is changed, you know. I could cope perfectly well with my three kids, but now I feel I could put them into fostering or something, you know. Over the three year period [since gaining custody] I've never had a good holiday, nowhere. I can't find myself any more, you know. You tend to forget about yourself. I tend to forget about shaving, you know, or even a wash, and I think your health tends to go back on you. But this has only occurred because of the marriage breakup ... I have all the responsibility, especially when it comes to incontinence. I have to get on with it, you know, which can be a bit of an ordeal, you know.

This man's account gives some insight into the ways in which health can interact with other variables - family composition and size, respite (or lack of it), subjective perceptions and characteristics of the child - to cause considerable stress and deplete coping effort.

Variations also emerged in parents' perceptions of the factors which contributed to their ill-health. Some were reluctant to view the child's presence as a precipitating factor and identified other causes, such as moving house and financial worries. However, almost three-quarters of those who reported ill-health believed that the demands of caring were a major cause. Several expressed the hope that regular respite would alleviate stress and ease fatigue.

Social and Support Networks

(i) Informal Networks

Intrafamilial resources and social supports may be viewed as complementary aspects of a whole coping strategy (Schilling, Gilchrist and Schinke, 1984). These authors have also identified three levels of social networks available to parents of handicapped children: firstly, family household members, (which have already been examined) secondly, extended kin and relatives and, thirdly, neighbours and friends. It was noted in Chapter 2 that the practical

contribution made by extended family, friends and neighbours towards the care of a child with disabilities is relatively low (Wilkin, 1979; Kendall, 1982). On the other hand, sharing the tasks of caring both within and outside the family has been associated with effective functioning (Venters, 1981) and an ability to maintain the child at home (German and Maisto, 1982). It is also important that families should perceive as helpful those supports which they do use. However, the existence of 'support networks' is not necessarily effective in protecting the individual from stress; for example, a dense family-dominated network can give rise to stress while a more diffuse network of friendships may reduce it more effectively (Kazak and Marvin, 1984).

Consistent with the findings of Waisbren (1980) and German and Maisto (1982) it emerged that the child's grandparents provided the most frequent contact and support within the informal network. Twenty-one families saw at least one grandparent regularly, that is at least once a fortnight, and 11 families had the same level of contact with other relatives as well. A substantial proportion had a fixed weekly arrangement to visit or be visited by members of their extended family. Seven families, however, did not see any relative on a regular basis; in three cases, this was due to distance. It was not clear whether this made any significant difference to coping abilities. Three, for example, had well-developed friendship networks which offered regular, practical assistance with childcare, while two had evolved a 'self-sufficient' coping style.

However, the importance of family supports to most of the sample is shown in data relating to parents' most recent contact with their relatives. Eight families had seen a relative on the day of the

interview, and a further 15 within the past week. In most cases the relative last seen was the child's grandparent. Nine families had relatives (again mainly grandparents) living within a mile and a further eight had relatives within ten miles. Only four families had no relatives living nearer than 50 miles away. Two-thirds of the sample received some form of assistance in childcare from their relatives, usually grandparents. The bulk of this support took the form of childminding, although it might include housework, taking the child on outings or, in seven cases, having her to stay for short periods. Four families could expect to receive help for at least a weekend and six for up to a whole day.

However, it is important to stress that most couples (15 out of the 20) were aware that this source of help was finite, due to their own parents' increasing age and decreasing physical strength. Fears were expressed that grandparents were already doing too much:

Both our parents are getting on now. I worry that they won't manage Jimmy. He moves so fast and you have to move fast to keep up with him.

These parents were now looking for alternative sources of support which could gradually replace the help currently provided by grandparents. A few had brothers or sisters who occasionally took the child out for the day or with whom she stayed for a weekend. Overall, however, assistance from the extended family, other than grandparents, was very limited.

About a third of the sample reported that they had little contact with their neighbours: in some cases a sense of social isolation was expressed. Others knew one or two neighbours or reported a significant level of community spirit in the

neighbourhood. Several parents socialised with their neighbours and thought of them as friends.

Thirteen families received some practical assistance in childcare from their neighbours, which mostly took the form of childminding, while regular assistance with day-to-day physical care, such as bathing or feeding the child, was rare, echoing Wilkin's findings (1979). Most parents felt that it would be unfair to ask their neighbours to look after the child for more than a couple of hours. However, a few had reciprocal childminding arrangements which worked well.

Friends were less likely to help with childcare than were neighbours, but seemed to play a more 'social' role although some clearly offered emotional support. However, only 12 families had regular contact with friends, while ten had limited contact (meaning 'occasionally' or with one person only). Eight families reported that they had no friends, including several who have already been described as facing social disadvantage.

Eight families had received some help from friends in caring for the handicapped child over the past year. Again, this mainly involved childminding although a couple of children had stayed with friends overnight. Several respondents reported that although friends had offered to childmind, parents felt that they lacked sufficient knowledge or understanding of the child to do so. Furthermore, a strong belief emerged among many families that it was not 'right' to ask friends for help especially when one was unable to reciprocate. One father commented:

No, no, we have no friends that ... I don't think we have ever had friends who actually, we have been able to use even to babysit, to that extent. I mean it has always been a thing within the family rather than ... I don't think we would ever burden friends with that.

While a mother explained:

All my friends have got their own children, I mean they have all got two of their own. No, you can't possibly ask someone else in that position to take your son.

It is important to take note of these parents' natural antipathy to the idea of asking friends to look after their children since they were later encouraged to develop 'friendly relationships' with their carers by the Share-the-Care Scheme.

Indeed, whatever level of informal support they received, a large majority of parents reported great difficulty in asking for help outside the family. Some simply avoided asking anyone, even if it meant considerable inconvenience to themselves:

Very difficult. I avoid it like the plague. We don't ask anyone.

A principal reason for this reluctance was a fear of abandoning what they saw as their parental responsibilities. One father said:

It is like anything else, you don't like putting your kid into other people's hands - you know, the responsibility of your kids onto other people.

In Chapter 1 I discussed in some detail certain facets of the present political climate which emphasises the values of self-sufficiency in general and the virtues of parental responsibility and the 'privacy' of family life in particular. In this context, asking for support may seem to represent an admission of personal inadequacy and/or a failure in good parenting. The pressures to continue 'coping' under considerable stress are very real, as this mother's comment indicates:

I don't like imposing on other people because I
feel she is my child and I should ... I should cope.

In Chapter 2 attention was paid to the ambivalent feelings which parents commonly experience in relation to shared care (Backett, 1982; Bryant, Harris and Newton, 1980). Hill's classification (1984) of exclusive and inclusive attitudes towards sharing care was also discussed. Parents with 'inclusive' attitudes believe they have a responsibility to organise the provision of childcare but do not feel bound to act as the child's sole caretakers, whereas those with 'exclusive' attitudes believe they have a duty to personally provide the bulk or totality of childcare and would consider it wrong to ask others to do so. The former group is likely to see benefits for the child from having a range of stable caregivers: the latter see the child as in need of protection and one-to-one relationships. Many parents in the present sample could be said to fall into one or other category while a few appeared to express both attitudes to some degree. Clearly, these factors are likely to play a vital role in relation to the application to Share-the-Care, as will be discussed shortly.

Finally, it may be noted that just over half the sample were dissatisfied with the level of informal help they currently received (see Table 4.12), but again these responses were not related in any obvious way to actual levels of support. Some who declared themselves satisfied received a very low level of informal support, but presented this as a positive choice:

I don't ask for any help. I am very independent.
I have got used to doing everything for Sally and I
just get on with it.

Data?

TABLE 4.12 Parents' Satisfaction with Current Levels of Informal Support

Level of satisfaction	Number of families
Satisfied	9
Mixed feelings	5
Dissatisfied	16
Total	30

(ii) Use of Services

Overall, the sample used few formal services. High satisfaction was generally expressed with the voluntary sector, particularly Barnardo's West Lothian Family Support Service and the North Edinburgh Action Group. Statutory services met with less approval, mainly on the grounds of their limited scope and accessibility. One mother remarked:

It is a game of Hide and Seek. If you can find it
you can get it. If you can't find it you don't.
If you don't ask, you'll not get.

Similar findings regarding the ineffectiveness of services in enhancing daily coping have been made by a number of studies, as noted in Chapter 2 (Wilkin, 1979; Lloyd Bostock, 1976).

One type of service worth mentioning, however, is weekly social or recreational clubs for children. Chetwynd (1985) found that parents whose children regularly attended such clubs experienced less stress. In the present sample, 18 out of the 31 children were using this kind of service at least once a week. Not only would this accustom them to mixing with people outside their home and school, thus serving as good preparation for use of Share-the-Care, it would also provide parents with respite of a frequent, reliable and local kind.

(iii) **Contact with Professionals**

About half the sample had a social worker (outwith the Share-the-Care Scheme) and in most but not all cases they had found this support useful. Among several families, however, there was a marked tendency to distance themselves from any need for a social worker, which clearly represented a stigma in the eyes of some. One father described the function of a social worker as to support those who are:

stupid, sick and ignorant and get up to
the most abysmal things with their lives,
not for the likes of us.

It may be speculated that this attitude could create certain difficulties for parents in relation to using Share-the-Care since this involves a certain amount of contact with social workers.

Data collected about other professionals proved extremely difficult to analyse. This may have been due in part to weaknesses in questionnaire design, attempting to cover an extremely broad area which could constitute a study within itself by means of a few questions. However, a second unforeseen factor arose: over a third of the sample voluntarily related, sometimes at considerable length, an account of events surrounding the child's birth, diagnosis or later complicating conditions. These stories all centred on perceived negligence on the part of the medical profession and, even when they had occurred several years earlier, clearly such events still caused parents considerable distress and/or anger. use
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This unexpected finding gains added significance in that early intervention is an area identified by Cunningham and Byrne (1985) as being of potential theoretical relevance to the transactional model. Recent thinking in this field highlights the need for parents to work through their feelings about having a handicapped child at the point

of birth or diagnosis. The extent to which this task is successfully completed is thought to be crucial in determining future adaptation and levels of service utilisation (Cunningham, 1979).

It is interesting, then, that Bird (1982) evaluating the Pact Respite Care Scheme, suggests that:

Parents need to have accepted their child's handicap and to have come to terms with many of the associated painful feelings before they approached the Scheme.
(p.19)

Unfortunately, however, because parents were not systematically asked about this topic, insufficient data exists from which to draw any conclusions. It seems reasonable to speculate, however, that harrowing experiences of the type described might effect parents' future attitudes both towards professionals and to service utilisation. Doubtless, this is an area which would repay further investigation.

Perceived Stress Among Families

(i) Assessing Levels of Stress

In the process of constructing a theoretical framework for the study, it was noted that families differ in the levels of stress which they experience (Folkman, Schaeffer and Lazarus, 1979). Cunningham and Byrne (1985) have warned against a tendency to conceptualise as a homogeneous group those with handicapped children who also differ, not only in levels of stress, but also in their styles of coping (Crnic, Friedrich and Greenburg, 1983). The preceding analysis of data has shown that considerable differences existed between the families in the present sample in almost every aspect examined - health, relationships, service utilisation and, most noticeably perhaps, in their attitudes and perceptions. It

would seem most important therefore to find a means of analysing this body of data as a whole, in order to establish any patterns which may exist both within and between families, particularly in relation to levels of stress. It was therefore decided to develop a simple classification which could subsequently be related to outcomes in terms of their application to, and use of, Share-the-Care. The creation of a new variable - levels of perceived stress - and the construction of 'stress groupings' has already been the subject of some discussion in relation to methodology.

In Chapter 2 the concept of stress was defined as:

A state arising from the actual or perceived demand-capability imbalance in the family's functioning ...
(McCubbin and Patterson, 1983, p.9)

The notion of 'goodness of fit' emphasises the importance of subjective perceptions, rather than objective measures, in the assessment of stress. It should also be borne in mind that low levels of stress can act as a positive force for adaptive change, while high levels representing a significant 'residue of tensions generated by the stressor which remain unmanaged', (McCubbin et al. 1980), are more disabling.

Bearing in mind these and other theoretical insights discussed at some length in Chapter 2, it was decided to select ten existing variables (see Table 4.13) from which to create a new one - 'level of perceived stress'. This exercise was performed in two different ways, one method being carried out by the researcher, the other by an interjudge who specialises in the study of stress in relation to health and behavioural change. The first method was undertaken on the computer, which performed a simple count for each case of the frequency of responses indicative of the existence of stress or

dissatisfaction, as reported by the families themselves. Thus, for example, in relation to the variable 'father's psychological well-being' a response which fell into the categories 'moderate' or 'severe' problems would register 1 'point', the maximum possible score being 10. A score of 1-3 represented low level perceived stress; 4-6 intermediate and 7-9, a high level of perceived stress (in no case was a score of 10 obtained). This count included some weighting, in that data indicating both 'moderate' and 'severe' difficulties in relation to certain variables would register 1 point, while only that indicating 'severe' difficulties were counted for other variables. Table 4.13 lays out the method in more detail, while Table 4.14 lists some examples.

TABLE 4.13 Assessing Levels of Perceived Stress Among Families by Computer Count

Variables	Coding Categories * (Value labels)		
Parents' satisfaction with time together	Satisfactory	Mixed feelings	<u>Unsatisfactory</u>
Satisfaction with level of informal support	"	"	"
Satisfaction with social life	"	"	"
Perceived effects on marital relationships	None/positive	Some strain	<u>Severe strain</u>
Mother's psychological health	Few/no problems	Moderate problems	<u>Severe problems</u>
Father's psychological health	"	"	"
Any perceived link between ill-health and caring	No	Cannot say	<u>Yes</u>
Child's behaviour	Few/no problems	Moderate problems	<u>Severe problems</u>
Perceived effects of child's presence on siblings	Positive	<u>Mixed</u>	<u>Negative</u>
Rewards child has brought	"	"	"

* Responses which fell into coding categories underlined were included in the computer count; i.e. were taken as indicative of stress/dissatisfaction

**TABLE 4.14 Computer Count of Perceived Stress :
Three Case Examples**

Variables	Example 1	Example 2	Example 3
Parents' satisfaction with time together		*	*
Satisfaction with level of informal support		*	*
Satisfaction with social life		*	
Perceived effects on marital relationships	*	*	*
Mother's psychological health			*
Father's psychological health			*
Any perceived link between ill-health and caring			*
Child's behaviour			
Perceived effects of child's presence on siblings			*
Rewards child has brought			*
Total 'score' = 1 (low level) 4 (intermediate level) 8 (high)			

* Are shown where individual responses indicated stress/dissatisfaction; i.e. where the computer registered one 'point'.

It is recognised that some families may have understated the level of stress which they experienced or which might be attributed to them by an 'objective' observer. However, within the study's theoretical framework, subjective perceptions are recognised as valid in themselves and indeed represent a potential coping resource.

A second method of analysis performed by the interjudge was more qualitative in style. She began by re-coding the written data by developing a Table which indicated for each case a 'positive, mixed or negative' response to the ten variables under consideration. She then examined the meanings and perceptions expressed in individual

responses, as well as the cumulative significance of all data obtained from the same family, as opposed to counting the frequency with which individual responses fell into pre-coded categories. In this way an overall assessment was made of 'low', 'intermediate' or 'high' perceived stress. These two methods of assessment produced an 80% agreement rate. Subsequent discussion with the interjudge resulted in the decision to move two cases from the 'moderate' to the 'high' perceived stress group. (One of these was a single parent who had scored highly on the computer count on all items relating to self, but had fallen into the 'intermediate' group only because of the 'not applicable' responses on items relating to fathers. However it was not felt that other single parents had been misplaced in this way.)

Table 4.15 indicates the final results of the analysis.

TABLE 4.15 Levels of Perceived Stress : The Three Groups

Levels of perceived stress	Number of families
Low perceived stress	11
Intermediate perceived stress	10
High perceived stress	9
Total	30

For convenience, these groupings will subsequently be referred to as the 'low psg', 'intermediate psg' and 'high psg'.

Having created this new variable, it was then possible to analyse the data in terms of the three groups, in order to develop a profile of each. Again this analysis was initially carried out on

the computer to establish some broad patterns, after which a more in-depth and qualitative exploration took place, returning to the original data and examining the meanings and interpretations given by parents to the items under discussion.

(ii) **Profile of Stress Groupings**

As the numbers in each group are so small, the use of percentages must be viewed with caution. However, they do serve as a convenient means of comparison.

Very little variation emerged between groups in terms of manual and non-manual occupational categories, but the distribution of 'socially disadvantaged' families was less even. They comprised 18% of the low psg, 30% of the intermediate psg and 44% of the high psg, suggesting, not surprisingly, that social disadvantage was a significant stressor in itself. There was no obvious link, however, between stress groupings and single parenthood. The gender of the handicapped children was not a significant factor, but differences did emerge in relation to age. The high psg tended to have younger children, over half being aged 7 or under. Yet in this group the handicapped child was more likely to be the oldest, whereas in both other groups over half the handicapped children were the youngest in their family. This indicates a number of families in the high psg who had several young children, which again may have acted as an additional stressor. The intermediate psg tended to have the largest families, over half having three or more children. 12

Turning now to the children's handicaps, it may be worth noting that five out of the six with Down's syndrome fell into the low psg. It is also clear that in many respects the children in this group were more likely to have severe handicaps than were others. 45% had

a severe physical handicap, a higher proportion required medication; they were the least verbal and needed the most help with washing and dressing. In contrast, however, only one parent in this group reported serious behavioural problems. The high psg, although most able to wash and dress themselves, had a greater incidence of double incontinence than other children and were said to require the closest supervision, 77% needing almost continual supervision. This may have been related to their higher level of mobility. It seems reasonable to speculate that these two characteristics contributed significantly to the stress experienced by parents. The intermediate psg included fewer children with a severe mental handicap than did others, although several had severe physical handicaps.

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The highest level of sharing childcare tasks between partners took place in the low psg while the lowest was found in the high psg. Housework tasks were also more likely to be shared in the low psg, but in both cases the differences were too small to provide clear evidence of association. Again, families in the low psg tended to have a wider range of informal helpers, particularly among their neighbours, while it was the intermediate psg who used the lowest levels of informal support. Indeed, families in this group were most likely to express 'exclusive' attitudes towards sharing care. The high psg made least use of formal services, but again the differences were very small. However, more marked variation emerged in relation to holidays. The low psg were most likely to have taken a holiday within the past year, which on average lasted longer than that taken by other families. Indeed, families in the high psg were least likely to have had a holiday in the last year and some, not for several years. Children in this group were also least likely to

attend a regular social club. Both factors point to a lack of any opportunity for respite in this group.

Inevitably, given the way in which the groups were constructed, the highest rates of marital strain, ill-health and problems connected to siblings, were reported by the high psg - 8 out of 9, for example, reporting severe marital difficulties compared to 2 out of 11 in the low psg. Perhaps the most significant differences between the groupings, however, lay in their attitudes and perceptions, reflecting something of their wider coping strategies.

The low psg usually defined most aspects of family life, including caring, in positive terms, tended to liken themselves to parents of non-handicapped children and to demonstrate 'inclusive' attitudes towards sharing care. One such mother described the experience of bringing up her daughter as follows:

It's fun, it is, it's enjoyable ... I mean obviously I don't like changing nappies all the time but that and the physical care she needs, I'm used to it. I have always thought the problem she's got ... her personality, herself, outweighs all the problems really.

Although the children in this group tended to have more severe handicaps than the rest of the sample, they also exhibited fewer behavioural problems. Their parents received slightly higher levels of both informal and formal support and appeared to have greater opportunities for a break. In short, substantial evidence emerged that these families were already coping effectively with their situations.

The intermediate psg were more likely to identify areas of difficulty in their lives but were reluctant to relate these to the demands of caring, preferring to suggest other explanations. They

often expressed a belief in personal responsibility for parenting and appeared to have adopted a self-contained and self-sufficient type of coping strategy, as this mother's comment illustrates:

It's my job to get on with it. We didn't have any professional help or therapy in the first couple of years, I did a lot myself.

The high psg, on the other hand, reported the most problems. They appeared to hold fairly negative views about the demands of caring and its impact on other aspects of family life. This may be related to the fact that children in this group were more likely than any others to be doubly incontinent, to exhibit behavioural difficulties and to require almost constant supervision. One father commented:

It's coping with yourself after it, at the end of the day. You are always up on the third level and you can't get down to the basement.

There was substantial evidence, then, that the coping strategies currently employed by these families were not proving effective in reducing stress to manageable proportions.

The finding that quite considerable differences existed between the three groupings in a number of areas suggests that the method used to construct them was a valid one. However, I will now return to an examination of the sample as a whole in relation to the applications to Share-the-Care.

The Application to Share-the-Care

(i) Hearing about the Scheme

A third of the sample had first heard about Share-the-Care within the past three months, another third within the past three to twelve months, the rest earlier than that. Ten had heard of the

scheme through the child's school, from teachers or other parents, and about as many through a social worker. Only five had come to know about the scheme through its own publicity.

(ii) **Motivation for Applying**

Six main areas of motivation were found among parents for applying to the scheme, which were by no means mutually exclusive. Broadly speaking the majority of the sample viewed the application as a means of strengthening their existing coping strategies, since joining the scheme would provide them with a regular break and relief from caring. However, the ways in which they saw this process in operation varied. Firstly, some parents emphasised that Share-the-Care would extend the child's social experiences and capacity for independence. This development was considered desirable both for the child in the short-term and for the family in the long-term, one father commenting:

We are acting on other people's advice, to let Emma get used to other people handling her when she is very young. Other parents have problems because they've not let the child go until she is older.

Similarly, the mother of a 10 year old child with Down's syndrome explained:

Share-the-Care will be good for John in a lot of ways, for his own development. I don't expect him to live at home for the rest of his life, so the more preparation he has at coping well on his own in appropriate circumstances, the better for all of us.

Secondly, some parents hoped that regular respite would allow them to spend more time with each other and with their other children. Thus, one mother commented:

Over the past year Stephen has become far more aware of his brother's handicap and how it may restrict him. He could go fishing with his dad, I could have me to myself. We could all go somewhere, the three of us overnight.

Thirdly, and on a similar theme, parents believed that joining the scheme would create more free time for other family members to pursue their own interests, without the demands and restrictions imposed by caring. This can be related to a comment made by Turnbull et al (1984):

Healthy family life involves a complex balancing of individual group interests. Equal importance should be allocated to the well-being of every family member.
(p.117)

Fourthly, some parents wished to secure a form of back-up support, should an emergency arise or a failure occur in primary caretaking arrangements. This might be termed 'contingency' planning and points to a drive within these families to take control of their circumstances, a factor identified by Folkman, Shaeffer and Lazarus (1979) as important to stress management.

Broadly speaking, these four areas of motivation were most often expressed by the low psg families.

Fifthly, families who were under considerable pressure and experiencing difficulty in coping - 8 out of the 9 high psg - applied to the scheme with more immediate objectives in mind: to obtain a rest and some relief from stress. This single parent, for example, commented:

I want someone very soon to take the children
-like today ... because I'm worn out.

And another parent said:

There are times when I feel to myself - I wish the carer would hurry up - I wish someone would share it.

Included in this number was a single father who had requested the local authority to take his daughter into care, such was the level of breakdown in his family's coping strategies. In response, he was directed to Share-the-Care.

Sixthly, many parents - and this applied to all stress groupings - wished to secure a family-based service because this was perceived as more child-oriented than residential or institutional settings, and therefore likely to provide a better quality of care. As already noted, several respondents made complaints about hospital care. However, it is important to emphasise that there were exceptions. Two families at this stage expressed a preference for respite within a hospital setting.

Finally, it must be noted that at least six families appeared to have applied to the scheme only because they had been persuaded to do so by professionals (all outwith the Central Share-the-Care team). These parents were able to identify little or no other reason for doing so, and most appeared highly ambivalent about using the service. These tended to be parents who valued self-sufficiency, wished to keep the family unit together and were resistant to the prospect of separation. Once such mother commented:

We are feeling a bit pushed into it, it's all been done over my head. I wouldn't dream of going on holiday without Jill. My social worker has gone on and on about it, until I said OK, maybe just to please her or because of pressure (to agree).

Oswin (1984) has drawn attention to the dangers of assuming that the child's absence will be a pleasure to parents. She condemned the

practice she found among social workers of pressurising parents to use residential short-term care against their will.

One mother reported that use of the scheme had been stipulated as a condition of fostering a handicapped child, while another clearly associated the 'proposal' that she join Share-the-Care with her daughter being allowed home after a period of RIC on grounds of suspected non-accidental injury. Thus, a scheme which hinges on parental choice and control - on voluntarism - was being used almost as if it had a statutory component, or so parents perceived it.

These families are distinct in that their reluctance to join the scheme outweighed any positive motivation. However, some degree of ambivalence surrounding the applications was common throughout the sample.

(iii) Ambivalence about Joining the Scheme

It has been noted in relation to other family-based respite care schemes that parents are likely to show considerable initial ambivalence about joining the scheme (Smith and Smith, 1979; Banks, Grizzell and Strettle, 1984). Most parents in the present sample expressed some reservations about joining the scheme, although these varied greatly in degree and type. Some worries were issue-specific and practical in nature. For example, one mother was concerned about carers' abilities to cope with her daughter's extensive daily medication and risk of epileptic seizure. Others focussed on the less attractive aspects of physical care, such as applying suppositories, incontinence and 'constant dribbling'. They wondered if carers would be willing to handle these matters. Several parents referred to their children's difficult behaviour. For example, one mother whose child had a habit of self-mutilation, commented:

I can't say how another family would get on. It's up to them ... the hardest bit is accepting what she does.

Some parents, then, who experienced caring as stressful and problematic and who wanted a break which involved the temporary removal of the child from the family, found it hard to accept that another family, usually unknown to them, was willing - and, indeed, had volunteered - to assume that care. They experienced some curiosity, if not scepticism, about the carers' underlying motives:

Why do people want to do this? Why? What's lacking in their lives? Have they got so much love to give?

And again:

We wouldn't want Jane to be used as a substitute for anything, nobody with a hang-up.

At the extreme, fears were expressed that by joining the scheme, the child might be laid open to physical and/or sexual abuse. At whatever level, however, these various perceptions could interact to produce a generalised anxiety and guilt (a word used by parents) about their application.

Some parents also expressed anxiety that using the scheme might represent to others, or indeed to themselves, some inadequacy on their own part. Not surprisingly, these feelings tended to be strongest in those who felt they had been persuaded to join the scheme against their will, but it was also present, to a varying extent, amongst all those who had expressed 'exclusive' attitudes towards sharing care of their children; that is, who felt they would be abandoning their proper parental responsibilities if they asked anyone outwith the immediate family, except perhaps their own

parents, to look after the child. Similarly, there was a natural possessiveness among some parents which was threatened by the prospect of the child becoming attached to others. One father commented:

It could be hurtful to see Robert going off happily with someone else, a wrench, like his first day at school.

As this remark indicates, concern was felt not only that children might be homesick while at the carers, but that parents too would greatly miss their sons and daughters, sometimes to the extent that the proposed respite was hardly an attractive prospect. One single parent observed:

I have probably made her too dependent on me, but what else can I do? I have no husband, so we'll both feel it when we are apart. I shall miss her. I'll be lost.

The nature of previous separation experiences played an important part in determining current attitudes towards future separation, a subject which is discussed in more detail in Chapter 8.

However, it would be misleading to imply that a majority of parents expressed great ambivalence. About a third of the sample appeared to have considerable anxieties at this stage, and interestingly most of these families fell into the intermediate psg who, as already noted, tended to hold 'exclusive' attitudes towards shared care. In the rest of the sample, worries about using the scheme were outweighed by positive expectations, as the following comment illustrates:

I hate the thought of having to give Martin to somebody else, but it is going to be the best for all of us really.

The low stress group in particular held relatively open expectations:

Until we see how it goes, we don't definitely know how it will work out. It's a matter of waiting to see if there's a family suitable. I know lots of people who use it and say it has made a great difference.

Summary and Conclusions

An examination of the sample's personal and social characteristics indicated that it represented a wide cross-section of the population. While the children had a broad range of different disabilities, the majority did have severe handicaps, over a third being profoundly and/or multiply handicapped.

A number of practical, social and emotional aspects of family life were then considered, revealing marked differences between parents, particularly in their perceptions of caring and its wider impact. A largely qualitative method was used to construct three groups, reflecting these variations. The 'low perceived stress group' (N=11) generally defined caring and its interaction with other aspects of family life in positive terms; the 'intermediate' group (N=10) identified some areas of difficulty in their lives, such as marital or health problems, but were reluctant to relate these to caring, while the 'high perceived stress group' (N=9), tended to take a more negative view of their task and to perceive it as the root cause of other problems.

The main reasons identified for the application to Share-the-Care were as follows: to increase the child's social experience and capacity for independence, to create more time for other family members to spend together or to pursue their own interests, and, in the case of those who were experiencing considerable stress, urgently

to obtain a break from caring. At this stage, most parents expressed some degree of ambivalence about joining the scheme although this ranged in nature from straightforward practical concerns to more generalised feelings of anxiety and guilt. The nature of parents' attitudes towards sharing care of their children was clearly an important factor here. Finally, six families were identified who apparently had been persuaded to join the scheme by professionals against their will and for whom the prospect of being separated from their children was not a happy one. Many of the findings outlined in this chapter, particularly regarding the nature of parental values and attitudes, were later found to have far-reaching effects on their use of the scheme, as the following chapter will discuss.

CHAPTER 5

Parents as Consumers

Introduction

Fifteen parents from the original sample of 30 applicants were successfully matched to carers during the fieldwork period and constitute 'the consumer sample'. Their follow-up interviews took place after they had been using the service for 6-8 months. This chapter opens by exploring certain factors which may affect placement on the scheme but, for the most part, concentrates on parents' perceptions and experiences of using the service, ranging from their introductory meetings with carers to a final overview of the scheme.

The smallness of the sample precludes the use of statistical tests or percentages and particular care must be taken in interpreting findings relating to the perceived stress groupings whose numbers are very small. Nevertheless, some interesting differences emerge.

Factors affecting Placement on the Scheme

(i) Social characteristics of the consumer sample (N=15)

Over half the sample lived in Edinburgh and a third in West Lothian. Only two families were from Midlothian and none from East. These figures correspond proportionately to those in the original sample of 30 applicants. It has already been noted that the early development of the scheme in Mid/East Lothian was very slow.

In terms of socio-economic status, the consumer sample was almost equally divided between families from manual occupational backgrounds (N=8) and those in non-manual occupations (N=7). Similarly, about half were owner-occupiers and half, tenants of local

authority housing. Again, these figures appear highly representative of the whole sample but differ from findings made elsewhere. In both Avon (Robinson, 1987) and Cornwall (Caudrey, 1984) the majority of scheme users were white-collar workers. Only two of the nine families originally identified as 'socially disadvantaged' fell into this sample. Four withdrew while three remained on the waiting-list. Although no firm conclusions can be drawn from such small numbers, it may be speculated that the scheme has some difficulty in meeting the needs of socially deprived families. This observation does not apply to single parents, however, since all five from the original sample were matched within the fieldwork period, (including one family whose carers later withdrew and which does not therefore fall into this sample.)

(ii) Characteristics of the Children

The sample consists of six boys and nine girls ranging in age from 2-14 at the time of placement, their average age being a little over 8, as was that of the whole sample of 31 children. Although there is a slightly higher proportion of girls in the consumer sample compared to that in the original sample, the difference is too small to conclude that gender is a significant factor affecting placement. Nor is there any evidence here to suggest that outcomes are influenced by age.

However a marked pattern emerges in relation to degree of handicap and level of self-help skills. Almost half the children in the consumer sample had little or no mobility; two-thirds were doubly incontinent; almost half had very little or no speech. A majority could feed themselves but, as Table 5.1 illustrates, only one or two were able to dress, wash or go to the toilet without some

assistance, while about two-thirds required these tasks to be done for them.

TABLE 5.1 The Consumer Sample : Level of Children's Self-Help Skills

Child's level of ability	Feeding	Dressing	Washing	Toileting
Fully able	9	2	1	1
Needs help	1	4	5	4
Quite unable	5	9	9	10
Total	15	15	15	15

Compared to the figures given for the whole sample (see Chapter 4, Table 4.5) these findings indicate a lower overall level of ability among the consumer sample in each domain and correspondingly, on average, the need for a higher degree of support in these children than among those who were not placed on the scheme.

Furthermore, eight children had at least one severe physical handicap, compared to eleven in the original group of 31; for example, one was blind, another deaf and four had cerebral palsy. Most had a severe mental handicap. Over half the sample suffered from epilepsy, but in most cases this was well controlled by medication. No clear pattern emerged in relation to the children's behaviour. Although a large proportion of those who withdrew did report behaviour problems in their children (8 out of 10), it also emerged that half those with behavioural problems were successfully matched to carers. Nine of the 15 children in the consumer sample were said to have some level of behavioural difficulty. Ten were described by their parents as needing constant supervision.

These results clearly indicate that, contrary to what might be expected, the children who were successfully placed on the scheme had more severe disabilities and fewer self-help skills than the rest of the sample. The ability of family-based respite care to accommodate children with a high level of dependency has been demonstrated elsewhere (Fenwick, 1986; Robinson, 1987).

(iii) Levels of Perceived Stress

TABLE 5.2 Cross-tabulation of Perceived Stress Groupings with Outcomes in Service Utilisation

Levels of Perceived Stress	Outcomes in Service Utilisation		
	Matched	Waiting	Withdrawn
Low	9*	1	1
Intermediate	2	2	6
High	5	2	2
Total	16	5	9

* includes the matched family whose carers later withdrew

A chi-square test applied to this Table results in a 0.0572 level of significance. However, as 7 of the 9 cells have an expected frequency below 5, the Table is presented as an indicator of trend rather than evidence of association. Nevertheless, it is apparent that most of the families from the low perceived stress group were successfully matched while the intermediate psg were least successful. Indeed, a majority of their applications ended in withdrawal. Outcomes in the high psg were more varied. Secondly, however, the scheme is also able to accommodate some who are experiencing high levels of pressure and whose coping strategies are less efficient in managing stress. The fact that only two intermediate psg families appear in the consumer sample, along with


their tendency to withdraw from the scheme may be related to their 'exclusive' attitudes towards sharing care and their preference for a self-reliant coping style. These themes are explored in detail in Chapter 8.

(iv) **Summary**

In summary, the demographic characteristics of families did not emerge as a significant factor in relation to outcomes in service utilisation, although some indications were found that applications from socially disadvantaged families may not be successful. The age and gender of children did not seem relevant, but it was striking that a large proportion of those with the most severe handicaps and lowest level of self-help skills was placed on the scheme, while the more able children were less likely to be matched. This suggests that the scheme is catering primarily for severely handicapped children rather than those with mild or moderate disabilities and may partly reflect professional practice. However, it is worth noting that the average age of this sample was 8 and that although severely handicapped these children may have been seen as relatively manageable. The presence or absence of behavioural problems was not significant. The most marked differences were found in relation to levels of perceived stress and, by implication perhaps, styles of coping. These findings suggest that outcomes may not be affected so much by the child's characteristics as by the nature of parental perceptions and attitudes and the interaction of these with other variables. The role of the agency in determining outcomes is considered in Chapter 8.

The Interviews

The 15 families in the consumer sample were interviewed between



6 and 8 months after they started using the scheme. Due to variations in the length of time they had waited for the service, in matching procedures and in the pace of introductory visits, the second interviews took place with individual families between 7 and 16 months after their first one. These and related issues were discussed in detail in Chapter 3.

Four single parents and four couples were interviewed, but in seven cases, primarily due to parental choice, only the mother was present. All but two interviews were tape-recorded.

Length of Time Waiting for the Service

As Table 5.3 shows, over half the families were matched within three months of their application.

TABLE 5.3 Timing of Matches

Length of Wait	No. of Families
1 - 3 months	9
4 - 6 months	3
6 - 12 months	2
Over 1 year	1
Total	15

Most parents were very happy with the timing of their match although, not surprisingly, those who had waited over six months were less satisfied. The mother who waited longest linked the delay to the fact that her daughter was a teenager and wheelchair-bound. Another family, who waited seven months, referred to the fact that they had stipulated many criteria regarding the type of carer they wanted. Discussion with social workers would confirm that these

factors contributed to some difficulty in finding suitable carers for these families. However, parents commented that while they were waiting for a match, they had been kept well informed of developments by the social workers and did not feel 'forgotten'.

Preparation of Parents and Introductions to Carers

The importance of thoroughly preparing and involving natural parents in the process of placing their children in foster care has emerged as a key issue in that field of research (Aldgate, 1980; Triseliotis, 1988a). It has also been argued that parents who use child-minders might benefit from greater preparation (Bryant, Harris and Newton, 1980).

When a referral is made to Share-the-Care or an application received, a social worker visits the family in order to gather more information, verify the viability of the application and assess what type of carers are required. One visit or several may take place. In retrospect, a weakness in questionnaire design was the absence of any questions specifically relating to this area. It therefore remains unclear how far these discussions focus on practicalities and how much they extend to the exploration of parents' feelings and anxieties about sharing care. However, it was noted in the previous chapter that six parents felt they had been under some pressure from professionals, all outwith the central Share-the-Care team, to join the scheme. Two such families fell into the consumer sample. Both encountered difficulties in using the scheme, one having done so only once during a 7-month period. The others all withdrew. In these cases, it seems that professionals did not explore parents' concerns about joining the scheme fully, nor offer them effective reassurance, yet if parents do not receive adequate preparation it seems unlikely

that they will be able to prepare their children properly.

Social workers also have a vital role in judging the viability of potential matches and in linking carers and children who will meet each other's needs, as well as carers and parents who will be able to form constructive relationships. Most parents reported they had been 'well matched'. One mother commented:

I thought [the social worker's] skill in matching us was very good. He was sensitive to real needs on both sides.

Caudrey (1984), evaluating a pilot scheme in Cornwall, reports considerable dissatisfaction in both parents and carers when they were left to carry out their own introductions, without social work support. This poor beginning led to minimal use being made of the scheme and a substantial drop-out rate. In Lothian, once the potential carers have met the child at school, they then visit the family home. Social workers are always present at these meetings. The family usually then visit the carer's home, with or without the social worker, depending on the outcome of the initial meeting. Several parents commented that the latter's presence had helped ease awkwardness and facilitate discussion, while also ensuring that certain key issues were covered and information clearly exchanged. In one case considerable difficulties had arisen during the introductory meeting. The carers had prior experience of looking after two children through the scheme and it seems that their resulting self-assurance was misinterpreted by the parents as 'abruptness and over-confidence'. However, because the social worker had been present during this encounter, she was able to assess the nature of the interaction, and encourage the parents to try a second

meeting, during which she acted as a catalyst in resolving the problem. However, this couple did take longer than most to establish full confidence in their carers once the match began. These findings suggest, as Triseliotis (1987) has pointed out in relation to fostering, that the characteristics of parent, carer, social worker (and child) are inter-dependent and that each contributes to the success or failure of a match.

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The introductory meetings were valued by parents for the opportunity they gave to expand on written information contained in the application form regarding the child's likes, dislikes, familiar routines and so on. Perhaps more important, however, was their perception of the carers as individuals capable of meeting those needs and of forming good and easy relationships with their child. One mother reported:

We could see how very fond they were of children ...
They didn't just sit and talk to us. They spoke to
the children. That made quite a good impression on me.

The value of parents visiting the carers' home during the introductory stages was also stressed. Not only can this allay anxieties which parents might otherwise feel regarding the care environment, it can also serve as an important aid in preparing children, since parents can then talk to them in an informed manner about the carers' home. Caudrey (1984) found that parents expressed more difficulty separating from their child when they had not visited the carers' house themselves. Similar findings have been made by Aldgate (1980) in relation to fostering.

Three parents already knew their carers prior to joining the scheme, both parties having submitted joint applications. Where the

agency was responsible for making introductions, parents reported that these had been well organised and had gone smoothly, despite the potentially sensitive nature of the situation:

It was ... fine, I mean I found that [the carer] and I got on fine from the start. You tend to be on your best behaviour, which makes everything a bit artificial ... a bit like blind dates or something, perhaps not quite so terrible!

To summarise briefly, it would appear that the quality of preparation and introduction play a crucial role in determining the future success of a match and the importance of social workers being present during the first meeting should not be underestimated. While most parents appeared well satisfied with the organisation and outcome of the introductions, there may be a need for more thorough discussion and preparation at an earlier stage, prior to submitting an application.

Geographical Distance

As Table 5.4 indicates, most parents lived no more than 10 miles from their carers. From the agency's viewpoint, nearness of locale is an important factor in matching considerations. The importance of placing foster children near to home, thus minimising the disruption to their education and social networks, has recently been noted (Berridge and Cleaver, 1986). Oswin (1984) has suggested that parents using family-based respite care should not be linked to carers living further than 5 miles away. Only one father expressed a preference that his daughter's carers might live nearer at hand, the distance in this instance being about 10 miles.

TABLE 5.4 Distance between Parents' and Carers' Homes

Distance in Miles	No. of Matches
1 - 5 miles	5
6 - 10 miles	8
11 - 15 miles	1
16 - 20 miles	1
Total	15

Transport
rather than
distance

Use of the Scheme

As Tables 5.5 - 5.7 indicate, the most common pattern for 'visits' (i.e. occasions when the child spent time at the carers, be it overnight or daytime only) during the 6-8 months of use, was one weekend, usually including two nights, per month. Ten children had visited the carer between 6-10 times, the overall average being 9. Some children had spent a longer period at their carers while their parents were on holiday. These figures exclude introductory visits when the child was accompanied by her parents.

However, within this general pattern, there was considerable variation. One 5 year old visited his carer every fortnight but never stayed overnight, while another child had only used the service once in 7 months. A 3 year old boy regularly spent every second weekend at his carers. In some instances, there was cause for concern that factors relating to the timing, length and frequency of visits was giving rise to homesickness among children, an important issue discussed in detail in Chapter 7.

TABLE 5.5 Usual Length of Children's Visits to Carers

Usual length	No. of Children
Daytime	2
Overnight	5
Weekends (2/3 nights)	8
Total	15

TABLE 5.6 Average Frequency of Children's Visits to Carers

Average Frequency	No. of Children
Every 2 weeks	3
Every 3 weeks	2
Once a month	7
Less than that	3
Total	15

TABLE 5.7 Average Number of Visits

Average Number	No. of Children
1 - 5 visits	2
6 - 10 visits	10
11 - 15 visits	2
16 - 20 visits	1
Total	15

If these figures are compared to those reported from other schemes, it seems that families may use Share-the-Care for longer visits than is usual elsewhere. In Hounslow, 78 out of 120 placements in 1980 were for day care (Phelps, 1981). However, shorter visits may occur more frequently. Merton Social Services Department (1982) record that a daytime session once a week or fortnight was common.

About half the sample, mainly from the low psg, were satisfied with the length and amount of breaks they received. Two felt they did not need so many but considered it important to maintain continuity for the child's sake. Half the sample, including five of the six high psg families, indicated that while reasonably satisfied with the situation, they would have preferred more frequent or longer periods of respite. They were discouraged from attempting this, however, partly by a fear that the child might feel 'rejected', partly by reluctance to 'impose' on carers. These are significant points which will shortly be explored in more detail.

Methods of Negotiating Respite

A widely claimed strength of family-based respite care schemes is that parents are able to take the initiative in arranging periods of respite as and when they wish and, once introductions have taken place, social workers can withdraw to the background, as if leaving the matches 'to run themselves' (Pont, 1983; Bryant, 1984). The results of empirical research, however, do not on the whole support this view (Bird, 1982; Caudrey, 1984). Banks, Grizzell and Strettle (1984) report that difficulty in using the service was 'a constant theme' among parents in Oxfordshire. On the other hand, Robinson (1986), evaluating a service in which carers act as professional

workers and are remunerated accordingly, reports no such problems.

In this section, I will look at the methods whereby periods of respite were negotiated in Lothian; the underlying issues are explored in the following section.

Among the present sample, in only four of the 15 cases did parents report that they usually took the initiative in contacting carers to arrange a break, although the carers might invite the child to stay on a special occasion, such as a local gala. In three cases, parents reported both sides shared responsibility for initiating and making arrangements. A further three parents had a fixed ongoing arrangement whereby the child visited the carers at regular intervals, such as the first weekend of each month. This system had been proposed by social workers in order to facilitate the match, although responsibility for deciding on actual dates remained with parents and carers. It was most important for parents to know that flexibility and control was not lost through this system: it remained within their power to alter ongoing arrangements in accordance with changing circumstances. However, agency records indicate that in one case a regularised arrangement was introduced by social workers in order to offset the danger of over-use, since this was considered inadvisable for both child and carer. The parent concerned, however, was far from satisfied with this arrangement, feeling that it left no room for flexibility.

Five parents reported that they seldom asked their carers to take the child or would only do so for a special reason, such as when their house was being redecorated. In two or three cases, the match had been sustained by the carers regularly inviting the child to stay. Another family had relied on their social worker to act as a

'go-between' in making arrangements. One child, as already noted, had only visited her carer once in 7 months. Although this was considered satisfactory by both parents and carers, it may have been less desirable for the child, who was given little opportunity to form a relationship with her carers.

Five families had been turned down by the carer on one or two occasions, due to family illness or previous social engagements. Four of these were parents who found it difficult to ask and it may be speculated that this experience discouraged them from doing so again. However, they all perceived as valid their carers' reasons for being unable to have the child.

Table 5.8 illustrates methods of negotiation, as reported by parents, both in terms of the whole sample and the perceived stress groupings, while Table 5.9 demonstrates the degree of ease or difficulty they felt in asking.

TABLE 5.8 Methods of Negotiating Respite : Parents' Perceptions

Method of Negotiation	No. in whole sample	Low psg	Inter. psg	High psg
Parents usually take initiative	4	3	1	-
Shared responsibility	3	3	-	-
Regularised arrangement	3	2	-	2
Parents seldom ask	5	-	1	3
Total	15	8	2	5

TABLE 5.9 Parents' Reported Ease in Requesting Respite

Level of Ease	No. in whole sample	Low psg	Inter. psg	High psg
Easy	7	6	-	1
Mixed feelings	1	1	-	-
Difficult	7	1	2	4
Total	15	8	2	5

Of the seven families who reportedly found it easy to initiate arrangements only three regularly did so; the others had developed more mutual forms of negotiation. As the Tables show, interesting differences emerge between the stress groupings. Six of the eight low psg families regularly took it on themselves to initiate the arrangements or else shared responsibility for doing so with the carers. The two who did not clearly held 'exclusive' attitudes towards sharing care. Both intermediate psg families found it difficult to approach their carers, while families from the high psg were least active in making arrangements, four out of five experiencing difficulty in this respect.

Again, caution must be taken in drawing conclusions from these results when such small numbers are involved. Nevertheless the findings are varied and complex, indicating that arrangements which work well for one family may be unsuccessful in another. Nor would these results support generalised assumptions that parents using family-based respite will, of their own accord, organise breaks as and when needed. Similarly, it seems that while some carers will assume responsibility for sustaining a match, others may not.

Parents often accounted for their difficulty in asking for a break in terms of their own feelings about sharing the care of their children. This mother's comment about the scheme is typical:

I can't say there's a drawback in it, apart from my own slight guilt about using someone else to look after my child, but that's self-imposed, not a drawback.

Although this mother appears to draw a distinction between the operation of the scheme and her own feelings about sharing care, it seems likely, in line with Silverman's thesis (1985), that the subjective experiences of using the scheme are to some extent dependent upon its 'objective' structure. In the following section, however, attention will focus on the explanations invoked by parents to account for their reservations about using the scheme and thus their difficulties in negotiating respite.

Factors Relating to Parents' Difficulty in Using the Scheme

It is fair to say that some level of concern about using the scheme existed throughout the sample, although varying in degree and persistence. While six of the seven low psg were able to overcome their reservations relatively quickly, other parents encountered greater difficulty. The nature of these concerns can be classified under four broad headings: attitudes towards sharing care, reactions to separation, anxieties about imposing on carers and, lastly, impaired organisational ability, due to stress. Although these factors were to some extent interdependent, they will be discussed separately for greater clarity.

(i) Attitudes towards sharing care

Parents of non-handicapped children have expressed feelings of

unease and guilt about sharing care, especially outwith their informal networks (Bryant, Harris and Newton, 1980; Backett, 1982). Their attitudes may be related to cultural values, family dynamics and/or to the prevailing social climate and political ideology. It was noted in Chapter 4 that many parents in the original sample of applicants could be classified as holding 'inclusive' or 'exclusive' attitudes towards sharing care (Hill, 1984) although some displayed elements of both. There is no doubt that these orientations had considerable influence on the degree of ease or difficulty which parents experienced in using the scheme.

For example, one mother from the low psg had remarked during the initial interviews:

Share-the-Care will be good for Victor in a lot of ways - for his own development. I don't expect him to live at home for the rest of his life, so the more preparation he has at coping well on his own in appropriate circumstances the better off for all of us.

Here she articulates a 'social exposure model' towards sharing care (Hill, 1984), perceiving the child as likely to benefit from contact with a range of people and from increasing independence. Commenting on how easy she found it to make arrangements with her carers, she now said:

No problem at all. I don't feel like I am asking for a favour. I know they wanted to be carers. I feel like we are in it together.

This mother saw her parental responsibilities lying in the organisation or provision of childcare, rather than feeling she should always look after the child herself, thus legitimising the use of substitute carers.

Another parent, from the high psg, made this comment prior to joining the scheme:

I don't like imposing on other people, because
I feel she is my child and I should ... she's my
responsibility and I should cope.

The 'attachment model' emphasises the importance of parents caring for the child in person, as well as the latter's continuing need for protective, one-to-one relationships within the family. These parents also worried that the child might feel rejected and 'sent' to the carers; this further discouraged them from arranging breaks.

When parents first applied to the scheme, the concept of carers represented, for most, an unknown quantity. In the majority of cases, however, once they had met and got to know their carers, these concerns were eliminated or greatly reduced (see next section). Thus, at this stage of the analysis, it would appear that where doubts remained about sharing care, these were related more to the general desirability and 'ethics' of doing so rather than to aspects of the particular care situation.

Parents' 'guilt' about using the scheme may be exacerbated by lack of previous service input. Due to the slow and problematic development of community care, relatively few services are available to this client group. In particular, those with older children have little experience of using services as this mother's comment poignantly affirms:

Services now are much better than when Muriel was
a baby. We just had to get on with it ourselves and
I thought I was the only mother in the world with a
handicapped baby.

Such parents may feel that having survived for many years with little external assistance, to avail themselves of support now would somehow represent inadequacy on their part. Again, where care

routines are long established and attachments and dependency particularly strong, the introduction of respite care may be considerably disruptive, as I shall now discuss.

(ii) **Reactions to Separation**

Oswin (1984) found that adverse reaction to separation, on the part of both child and parents, was a major stumbling-block to successful use of residential short-term care. During the initial interviews for this study, several parents expressed anxiety about being separated from their children. Those for whom this represented a major problem tended to withdraw from the scheme altogether.

Nevertheless, most of the consumer sample had been concerned about how the child would settle at first. One mother, from the low psg, commented:

We were worried about whether she would settle at night and would she be all right. We stayed about half an hour and then we went and she was fine.

As the match got underway, most parents felt reassured on this point. However there were some exceptions. Firstly, as already noted, some parents worried that using the scheme had made the child feel 'rejected'. Secondly, four parents had noticed evidence of distress in the child, associated with visiting the carers. The behaviours reported were disturbing ones: prolonged screaming and crying at the carers, clinging to mother on arrival, refusing to return there and regurgitating. Explanations given for such reactions were, on the one hand, boredom and lack of stimulation, on the other, adverse separation reactions relating to the close attachment between mother and child. In all four cases, the children concerned had few or mainly unhappy previous experiences of separation, indicating a need for family-based respite care to be

available, in some form, from an early age. Chapter 8 deals with the issue of homesickness in detail. However, it may be noted here that a small minority of parents were discouraged from using the scheme because they perceived it as distressing for the child and thus for themselves.

Although most parents had missed their child to some extent, this did not prevent them from enjoying the benefits of respite:

I miss her when she is away, but I don't sit and pine.

However, in a couple of cases, parents felt lost without their child:

When she's not here I'm useless. I miss her an awful lot ... when she goes up to [the carers] for the weekend, and I am here, I usually find that I end up starting at the top end of my house (cleaning) and go right the way down to the bottom for something to do, because I hate doing nothing, just sitting thinking, 'well, what is she doing now?'

grief
response
guilt
remorse

Again these reactions occurred among parents who held 'exclusive' attitudes towards shared care and whose lives tended to revolve around caring. The removal of the child from the family appeared to create more stress than it relieved; regular routines were disrupted, leaving a sense of emptiness and loss of purpose. It was noted earlier that the scheme can readily be conceptualised as a social support, the purpose of which is to reduce stress, but in this context, its potential to act as a stressor can be better appreciated. Similarly it has been noted that certain coping mechanisms may increase the risk of disorder, if used inappropriately (Rutter, 1981). It seems possible, then, that in some cases use of family-based respite care may come into conflict with the nature of existing coping styles.

One father, for example, from the intermediate psg, reported that using Share-the-Care had created tensions within the family, since their daughter's absence made them realise how 'handicapped' they usually were by her presence.

It actually brings home to you how different we are as a family from other families and that in itself makes you somewhat ... it can make you feel quite bitter in a way - the old 'why me?' syndrome, and I think Share-the Care can cause that kind of self-doubt and questioning.

re-aroused

Thus, the experience of respite had reawakened feelings of ambivalence and resentment about parenting a handicapped child, feelings which were normally subsumed in the daily demands of caring. These parents experienced considerable difficulty in 'letting down the guard', that is, in switching off and relaxing, apparently in fear that their enjoyment of the child's absence for short periods might lead them to wish for it on a more permanent basis.

The relationship between use of respite and admission to long-term care is probably a complex one. Oswin (1984) has suggested that where homesickness during respite creates or exacerbates behavioural difficulties, this may precipitate admissions to care. There is no evidence that parents' increasing enjoyment of respite creates such a dilemma, but, as these parents recognise, it may bring to the surface repressed feelings of ambivalence. Such fears may help to explain why some parents worried about their child feeling rejected, while another desperately spent her 'breaks' spring-cleaning the house.

These findings demonstrate that use of family-based respite care is not necessarily a simple, straightforward matter but can involve complex emotional and psychological reactions, some of which may be

disturbing for parents. They also indicate that a high level of social work support would be required in some cases.

(iii) **Anxieties about Imposing on Carers**

Several parents expressed anxieties about 'imposing' on their carers, particularly if the latter were perceived as busy people with other commitments and children of their own. Hill (1984) found a similar concern among his sample about encroaching on another family's autonomy.

Several parents had established reciprocal childminding arrangements with their neighbours. These seemed to work well, probably because they were seen to involve a fair exchange on both sides. Parents were less certain, however, how to repay or thank their carers for looking after the child. Some gave them presents; two or three believed that carers should receive more substantial payment from the agency. Here, parents were following a basic rule of social exchange:

An individual who supplies rewarding services to another obligates him. To discharge this obligation, the second must furnish benefits to the first in turn.
(Blau, 1967, p.89)

Some parents, who perceived their carers as motivated to join the scheme through altruistic feelings, were further discouraged from asking for a break, as if 'excessive' requests for respite might eventually satiate supplies of goodwill. These findings indicate the need for clearer guidelines from the agency.

It also emerged from the first interviews that parents were loathe to ask their friends for assistance in childcare and, since they were encouraged by the agency to develop 'friendly relationships' with their carers, it is not surprising that similar

misgivings arose here. Some schemes operate a voucher system, whereby parents are issued with a book of tokens and give so many of these to the carers in exchange for periods of respite. The carers then present these tokens to the agency in order to claim payment.

Finally, fears of imposing were exacerbated where care of the child was seen as particularly difficult or demanding:

I feel guilty at the moment because Donald is going through a bad patch and screams a lot and can be difficult to look after.

In these circumstances it was felt unfair to ask someone outwith the immediate family to look after the child. However, it may be speculated that some parents had a secret fear that carers would in fact be able to cope with aspects of care which they themselves found difficult. Indications that such was the case emerged more clearly among those who withdrew.

(iv) **Impaired Organisational Ability**

Campbell (1983) has argued that the format of family-based respite care schemes may discriminate against families who lack organisational skills, such as timekeeping, the ability to forward plan or even to use the telephone. In the present sample, impaired organisational ability among families from the high psg was a significant obstacle in their capacity to negotiate respite. Some tended to delay asking for a break until the home situation was very tense, which in itself could further incapacitate their ability to secure external support.

One mother commented:

I had found it quite difficult to ask for help and it tended to be when things were absolutely desperate - I just want him away because usually I am at the end of my tether.

In these circumstances the child may feel he is being removed as a direct result of some wrongdoing on his part. It is significant that two carers matched to high psg families believed the child perceived respite as a punishment. In Chapter 2, the concept of 'energy sinks' (Bubolz and Whiren, 1984) was used to suggest that a certain amount of energy is required to secure and utilise respite care. In the early stages of their matches, these families not only lacked energy, they were also understandably reluctant to expose to others the extent of their felt neediness:

I did need prodding because I felt very ...
I felt terribly needy and I didn't know how to ...
how to reasonably go about setting it up. It
sounds stupid, because I am quite intelligent.
I could have done it, I can do it now, but I
couldn't do it then.

As this mother's comment indicates, the families concerned recognised their dilemma and reported a gradually increasing ability to plan ahead and request respite. All felt optimistic about the future of their match. This change was due in part to their growing trust in the carers, but also to their own increasing enjoyment of respite. Equally important in resolving their difficulties was social work support. Not only did these families welcome this support, it seems that, without it, they might have dropped out of the scheme altogether. However, one or two parents would have liked more input from the social worker at the beginning, not only to bring both parties together in order to arrange mutually convenient dates in advance, but also to sanction their use of the scheme:

If someone had just given me permission to ask
as much as I wanted to, that would have been a help.

(v) **Summary**

In a checklist for 'positive community orientation in the development of respite care', Stevens (1987) includes the following item:

Parental control - of care periods, negotiated
direct with carers,
(p.21)

as if implying that the service is a gift to parents which they will use with equanimity and ease. Far from this, however, the findings made above demonstrate that use of family-based respite care may not be a straightforward matter, but can raise complex and difficult issues for some parents. Arrangements which work effectively for one family may be inappropriate in another, pointing to a need for flexibility in the scheme's organisation. Since only a minority of parents may feel able to take responsibility for negotiating periods of respite, social workers have an important task in identifying those who need more support. Not surprisingly, these tend to be families under the most stress, while attitudes to sharing care also had a significant bearing on parents' ability to use the scheme. The findings also indicate the importance of social workers monitoring all matches closely, if unobtrusively, rather than assuming they can be left to 'run themselves'. Finally, it may be noted that similar conclusions have been reached by other studies (Bird, 1982; Caudrey, 1984).

Parental Perceptions of Carers

(i) **The Nature of the Relationship**

The development of friendship between parents and carers is generally seen as a prerequisite for family-based respite care and, indeed, a strength, since it is assumed that this will facilitate the

process of sharing care (Bryant, 1984; Shaw and Hipgrave, 1983). In the present study, however, two parents reported knowing their carers 'very well', seven 'quite well' and six, 'not very well'. There was little socialising between parents and carers outwith the child's visit. Indeed, as Table 5.10 indicates, over half the sample believed the carers should be seen as the child's friends (or aunt/uncle) rather than their own, in order to foster his sense of independence and his motivation to continue the visits.

TABLE 5.10 Family-Carer Relationship : Parental Perceptions

Type of Relationship	No. of Families
Aunt/Uncle for child	4
Other/mixture	4
Child's friends	3
Family friends	3
Childminder	1
Total	15

not
exclusive
category
of design
of Q.

However, there were additional reasons why parents preferred to remain 'friendly but not friends' with their carers. It seems that worries about the non-reciprocal nature of the arrangements would greatly increase if the relationship was one of friendship, since this would invoke an obligation to 'repay' any 'favours' received, such as the provision of childcare. Because true friendship implies an ongoing exchange of concern and considerateness of both sides, parents' fears of imposing on the carers would be exacerbated. Friends can only be called upon for help to a limited extent. Nor did most parents wish to become drawn into details of the carers' personal lives, or feel obliged to offer them support where appropriate. Thus, one mother reported that she particularly liked:

... not feeling I've got to rush back because I am intruding on friend's time. The feeling that the carer has taken this on by choice makes a big difference.

These perceptions are consistent with the reluctance expressed by a majority of parents during the initial interviews to ask their friends for help with childcare:

We've got plenty of friends around but we don't like calling on them too much ... it would spoil the friendship ... you become a burden to people and that's not on.

Two parents who had been friendly with their carers prior to joining the scheme experienced great difficulty in asking them to look after their child, preferring the social worker to establish a regularised arrangement. However, other parents held different views about the nature of relationships. One mother was at pains to emphasise the closeness of her friendship with the carer, seeing this as a linchpin of the match's success. Unfortunately, her perceptions were not shared by the carer, who resented the other's attempt to involve her in issues beyond the scope of the match, such as marital difficulties.

On the other hand, there was room for this type of support in at least one match. A mother whose children had previously been taken into care on grounds of suspected NAI was subsequently linked through the scheme to their emergency foster mother, with whom she had formed a good relationship. While her daughter had only visited the carers once in seven months, she regularly did so during school hours. This created an important source of support for the mother, (who described the carer as 'my pal') which the latter was happy to provide.

It is worth noting that the parent who perceived her carer as a 'childminder' was the only one who expressed great dissatisfaction with her match. She believed the carer was motivated mainly by financial interest and chose this word to denote an impersonal business relationship.

Finally there was no evidence of a link between the psg groupings and the perceived nature of the relationship with carers, nor was there any association with social class.

(ii) **Trust and Communication**

Not surprisingly, a vital element in the development of trust between parents and carers was that the latter be perceived as offering a high standard of childcare. With one exception, the sample reported great satisfaction on this point, usually based on their judgement of the child's reactions, (see next section) and their observations of carers. In terms of activities and lifestyle, these parents appeared much better informed about the carers' household and the child's experiences there than were parents in Bryant, Harris and Newton's study of childminding (1980), in which ignorance about the child's daily routine at the minders was found to cause mothers considerable concern. It would be difficult to exaggerate the praise given by several parents in the present study to the ways in which carers looked after their child:

Very well. Paula needs somebody that is really tuned in and [the carer] is really exceptionally good with her ... she is a really nice girl and she goes out of her way to have friends round who have kids when Paula is there and takes her places and has crayons there for her. We think we have been very well matched.

Another important factor which reassured several parents was the knowledge that their carers had previous experience of looking after

people with mental handicaps, in their personal or professional lives. This suggested to parents that carers would be able to understand the child's special needs and respond appropriately, particularly if any difficulties arose. Some were able to cite particular incidents which had increased their confidence in the carers' ability to cope. Most parents perceived the carers as treating the child in similar ways to them; for example, by adhering to familiar routines. In one case, both sides had collaborated over toilet training, to ensure that the same words and procedures were being used in both settings. While consistency was generally considered important, four parents reported that the carers handled the child better than they did:

Maybe they are a bit stricter, which isn't a bad thing. We weren't strict enough to start with - they are showing her who's boss. We gave in to her too much.

Others contrasted the carers' fresh and energetic approach to stimulation with their own 'jaded' routines. It could be speculated that some parents might feel undermined by their perceptions of carers coping so competently, or even better than themselves, especially since they sometimes found it difficult to maintain a positive attitude towards caring. If such feelings did exist among this sample, it seems their effect was outweighed by the perceived benefits of respite. However, this reaction did emerge as a significant obstacle among some who withdrew from the scheme.

The establishment of trust in their carers was a vital element in allowing parents to relax and enjoy the break. Asked what were 'the best things' about the scheme, one mother replied:

Knowing there is somewhere Jenny can go that she enjoys, she's happy there and that they're people I can trust. I don't go away and worry what's going to happen if she's sick or has an asthma attack. I know they can cope - so I enjoy myself too.

Several parents compared their confidence in the care situation to the anxiety they had felt when the child was admitted to hospital, even for respite. However, one parent (who had described her carer as a 'childminder') expressed a preference for institutional short-term care. Her lack of confidence in the care situation was based on the following perceptions: she believed her son lacked stimulation and was bored and unhappy at the carers; that because the carers themselves had a profoundly handicapped child, her own boy was regressing; that the carer was a nervous anxious person, unable to cope with her own problems, who had joined the scheme for financial reasons and lacked a real interest in the boy. Data obtained from the carer in this case and discussion with social workers would not support these views. There was, however, evidence of considerable misunderstandings and poor communication between parent and carer, along with some indications that their interaction had the effect of reinforcing in each uncomfortable feelings about parenting a handicapped child. The original decision to match them was perhaps ill-advised.

Closely allied to the development of trust was the importance of good communication between both sides. Bryant, Harris and Newton (1980) found that, although relationships between mothers and minders were superficially friendly, talking together about the children was rare. Mayall and Petrie (1977), in an earlier study of childminding, discovered

Much distrust, conflict and absence of co-operation
between the two.
(p.30)

Most parents in the present study reported they had regular discussions with their carers about the child. These often took place at the beginning or end of visits, when carers would be brought up-to-date with the child's progress or parents given news about the current visit. In some cases telephone contact was sustained between meetings. Most parents apparently found their carers easy to talk to, the more so as time went by:

I find it very easy to talk to her. She's a very understanding person and she's got a good sense of humour.

However, there was evidence of poor communication in two matches and it later emerged that carers were more likely to report problems in this area (see Chapter 6). It was also noticeable that where parents did identify unsatisfactory aspects of the match, they had seldom raised these with their carers.

(iii) Differences in Lifestyle

Most parents could identify some differences in lifestyle between themselves and the carers; for example, in environment, family composition, mobility and leisure activities. These were mostly welcomed as enriching the child's experiences. In two or three cases, parents' relative openness to lifestyles unlike their own was in striking contrast to the tight criteria originally stipulated. During their first interview, one couple had stressed that their carers should be 'practising Christians'. They now declared themselves 'delighted' with carers who, while 'not regular Churchgoers', were nevertheless perceived as sharing similar values.

In terms of socio-economic status, six families were linked to carers of a similar background to their own, while nine were not. This generally went unremarked. The wife of a University lecturer, whose son's carers both had manual occupations, made the following observation:

Yes, there are differences. [The social worker] went into the differences in background at some length and wanted to know if we were concerned. I think it's good for Neil to see different types of home situation. Quality of childcare is the important thing.

In summary, it is striking that the many anxieties originally expressed by parents regarding what sort of people their carers might be and how they would manage to cope had failed to materialise. On the contrary, considerable satisfaction was now expressed, largely based on the development of confidence in the quality of childcare provided. Most parents preferred to perceive the carers as primarily the child's friends and several were wary of becoming over-involved themselves, believing this would obstruct the process of sharing care. Although differences in social background existed in over half the matches, this was not identified as a problem among the consumer sample.

Perceived Benefits of Using the Scheme

Parents were asked a number of questions relating to the benefits they perceived arising from use of the scheme. Table 5.11 shows their responses. Although the various aspects were to some extent interdependent, for example most parents were only able to relax because they perceived benefits in the scheme for the child, these will be discussed separately for the sake of clarity.

TABLE 5.11 Perceived Benefits of Using the Scheme

Perceived Benefit	No. of Families
A chance to relax	13
Freedom to pursue other activities	12
Benefits for the child	11
A sense of security	8
Benefits for siblings	6
Reduction in feelings of stress	5
Improvement in marital relationships	4
Enhanced ability to cope	3
Increased energy	2

(i) Benefits to the Child

As shown above, 11 parents reported that use of the scheme had brought certain benefits to the child; those who did not perceived the visits as distressing to the child. Table 5.12 analyses the responses in more detail.

TABLE 5.12 Perceived Benefits of the Scheme for the Child

Perceived Benefit	No. of Families
Child's enjoyment of visiting carers	11
Independence and broadened experience	10
Preferable to respite in hospital	8
Develops child's ability/potential	6
Enables parents to give better care	3

(a) Child's enjoyment of the visits

About two-third of the sample appeared confident that the child enjoyed her visits to the carers. This perception was based on their own observation of certain behaviours in the child, irrespective of her level of ability. These included:

- positive behaviour between visits: for example, talking about looking forward to the next visit; talking with enjoyment about experiences at the carers, or the carers themselves; wanting to phone them; packing a suitcase before a visit was due
- positive reaction on seeing the carers: for example, smiling, laughing, face lighting up, looking excited, clapping hands, running up for a cuddle, jumping into the carers' car, wanting to play with the carers' children
- positive reaction on return home: being 'full of bounce'; 'relaxed and in good shape'/'a little bit riotous'; eating and sleeping well
- absence of disturbed behaviour: for example, not screaming on arrival at the carers; not refusing food nor being 'clingy' on return; not refusing to visit carers.

Several parents emphasised the quality of the child's relationship with her carers and her evident fondness for them.

Parents also drew on information given them by carers. Sometimes this was a generalised report about the child's well-being, but often they repeated anecdotes illustrating, for example, how one child had become 'quite cheeky' at the carers, taken as a sign that she felt completely 'at home'.

However, there were indications in a couple of cases that carers' reassuring reports did not square with parents' own observations and intuitions:

I can only go on what the carer says, that Jenny enjoys herself when she's there. But her face falls when she sees the carer coming to the house.

Conversely in a few cases, parents' accounts of the child's enjoyment of his visits conflicted with data obtained from carers about his homesickness.

(b) **Independence and broadened experience**

Two-thirds of the sample reported benefits to the child in terms of increased independence or broadened social experience. They welcomed the opportunity for her to form relationships with new people and several liked the fact that she was also meeting carers' relatives and friends. The 63 mothers in Bryant et al's sample (1980) all reported that their child was happy at the minders and most felt she benefitted from going there, particularly from the opportunity to play with other children. Two-thirds also thought that learning to be away from their parents was a major benefit. Some parents in the present study referred to long-term benefits in terms of the child learning to separate from them. Although this could be a slow and sometimes painful process, one child's gradually changing perception of 'going away from home' as a punishment, to seeing it as a potentially enjoyable experience, was considered a breakthrough by her parents.

Oswin (1984) has condemned the practice of using short-term care as 'a preparation for adult life and independence' for young children, because she feels this would be abnormal for non-handicapped children. It may indeed be unnecessary to prepare under-fives for adult life. On the other hand, it must be remembered that, for a variety of reasons, many handicapped children are denied access to the types of preparation for adulthood which non-handicapped children enjoy. Indications have already emerged that minimal use of sparse provision may contribute to high level stress and/or adverse separation reaction on both sides. Where there are no signs of homesickness, preparation for future independence would appear to be a valid reason for, and a real benefit from, using family-based

respite. Oswin may be erring on the side of over-caution on this point. Again, Share-the-Care provides an experience which many handicapped children might not otherwise have - going to stay with friends - but which is considered 'normal' for most children.

(c) **Developing children's abilities**

Several parents felt the scheme provided an important learning experience for the child and identified tangible gains in her skills. Some commented on the carers' fresh approach to stimulation, involving the child in new activities and talking about different topics. One or two commented on improved behaviour which they attributed to respite:

When he comes back, he is less bossy and more mature.

Most parents, however, reported no differences in the child's behaviour since visiting the carers, although some mentioned changes which they attributed to other factors. For example, one toddler was said to have become more accustomed to other people handling her after one short stay in hospital; her parents did not believe that six months of visiting her carers had contributed to the change. It may be that some people would more readily attribute improvements in the child's skills or behaviour to professional 'intervention', rather than to the influence of another ordinary family. Indications will later emerge of marked differences in certain aspects of children's behaviour or apparent level of self-help skills while they were at the carers.

In summary, with one exception, parents in this sample perceived the quality of childcare offered by the scheme as being of a very high order. In addition, most were able to identify a range of

benefits arising for the child: in some cases, this related to his obvious enjoyment of the visits and attachment to the carers; in others, it extended to gains in his social skills or capacity for independence.

(ii) **A Chance to Relax**

The most important and valued aspect of using the scheme, reported by 13 families, was the chance to relax. The extent to which this affected daily life varied in degree from family to family. In several cases a regular opportunity to relax represented a welcome change. For example, one mother whose son required a high degree of physical care as well as having disturbed sleep patterns commented:

We don't need to listen out for Eddy through the intercom ... just knowing you don't have to get up at the crack of dawn. I can actually come downstairs and sit in the chair and not do anything, which is a lovely thought. It really is.

There was no evidence that feeling more relaxed was related to frequency of use. One family who had used the scheme only once in seven months felt more relaxed than before simply because they knew that a facility was available should they require it. Another mother who had used the service frequently still felt the need for additional periods of respite.

In Chapter 4, it emerged that families from the low psg did not generally refer to the need to rest or relax as a motivation for joining the scheme, but tended to present it in terms of their child's best interests. It is interesting, then, to find a small shift in this group's perceptions: after using the scheme for several months, they now expressed their own appreciation of regular respite and their enjoyment of the breaks.

(iii) **Reduction in Stress/Enhanced Coping/Increased Energy**

While most parents reported that respite had given them an opportunity to relax, several took this point one stage further, stating that it had been effective in reducing feelings of stress, or, as one mother put it, 'saved me from cracking up'. These were mostly families from the high psg who tended to identify the demands of caring as a major stressor and one which gave rise to other problems. Thus, one father said:

It's not all Tina's fault, but getting her away means we can all relax. We've no tension in the house.

In three cases parents added that having been refreshed by a break they felt better able to care for the child on her return. Furthermore, the knowledge that regular respite was available enabled them to cope more effectively between visits:

Now with David going away, I'm more ... you know I don't know, I feel more able to cope with him. I don't know if that sounds silly or no.

Two of these families now identified the carer as their main source of support, superseding their informal networks.

It seems that after some initial difficulties in using the scheme, when they had tended to delay contacting the carers until the situation was very tense, families from the high psg had begun to use respite on a more planned and regular basis. The resulting reduction in stress had, in turn, created more energy and opportunity for increased activity in other areas. Thus, one single mother reported that since joining the scheme, she had regularised access arrangements with her ex-husband, sought out helpful support structures for her children locally and joined a women's group.

There appears to have been a move away from their original motivation to join the scheme - an urgent need for respite - to a new objective of using regular breaks to prevent the accumulation of stress:

It's important that I don't allow it to get too desperate. If [my carer] has helped out regularly through the reasonable, mediocre sort of times, then presumably the desperation and the great need won't ... won't arise.

Although the numbers are very small this represents an important shift among the high stress group. It may be noted that this group reported the greatest number of positive effects. The high psg reported an average of five benefits per family, while the lowest rate was reported by the intermediate psg, 3.75 per family.

(iv) **A Sense of Security**

As parents' confidence in the care situation increased and they became accustomed to having regular breaks and relaxation, several developed a new sense of security. In some cases, this related to current childcare provision, in that should an emergency arise or a breakdown occur in primary caretaking arrangements, not only were the carers available to take the child at short notice, but the child was accustomed to staying there. Since a number of parents had reservations about leaving the child with friends or neighbours, such a sense of security represented a welcome change. The possibility of using the scheme in this way, as a means of strengthening existing coping strategies, had been a motivation for applying among the low psg and was now identified as a benefit by them. However, it was also cited by one or two high psg families, indicating again a shift in their perceptions.

Some parents presented their use of the scheme as part of a long-term care plan, with the main emphasis on future goals rather than immediate objectives. One father explained:

I don't think we went into the scheme with the idea of using it for special reasons only. This is a more long-term thing ... getting Gail to be less dependent on us ... Over the years to come, Gail is going to see a lot more of us than a normal child will see of its parents, and vice versa, and it should help her.

Developing a sense of control over future events is an important element in effective coping (Folkman, Shaeffer and Lazarus, 1979).

(v) **The Freedom to Pursue other Activities**

Most families reported a difference in the activities which they could pursue while their child was at the carers. The opportunity to have a pub lunch, to walk through the hills or to visit an art gallery may seem unremarkable to those who take them for granted, but were greatly appreciated by parents who were normally debarred from such pursuits. Twelve families had taken, or arranged to take, a holiday since the previous interview. In eight cases, the child was spending that time at the carers. This included four families who had not taken a holiday the previous year.

Using the scheme had created time for some parents to devote to other family commitments, including visiting sick relatives and catching up on domestic tasks. However, a very important point, made by several respondents, was the luxury of staying at home and doing nothing. It is important for carers to be aware that some parents were best able to relax by not feeling under pressure to do anything. Some signs of disapproval did emerge among carers that parents were not making the best use of their breaks.

One mother reported that not only had their social life improved as a result of using the scheme, but, arising from that, they had become more integrated in the local neighbourhood. It may be speculated that knowing their handicapped child had been accepted by another family also facilitated this process. A reduction in feelings of isolation is a significant indication of the scheme's success.

(vi) Benefits for Siblings

Five parents reported that Share-the-Care allowed them to spend more time with their other children and to involve them in activities which proved difficult when the handicapped child was present. This included three families from the high psg, who had made little reference to siblings in relation to their motivation for applying to the scheme. A sixth couple believed that their non-handicapped daughter benefitted from a break from her brother's aggressive behaviour.

However, there were indications that siblings in three families were not altogether happy about the respite arrangements. Two were said to miss the child while the third had been frightened of losing his brother altogether, and then a little jealous of his visits to the carers. Oswin (1984) suggests that siblings are likely to have adverse reactions to short-term care under the following circumstances: when the siblings are in infancy; when they have reached young adulthood and the handicapped child is younger; when the child was highly physically dependent or where there was only one sibling. While it might be argued that these variables cover most eventualities, at least one did apply in each case where siblings appeared less than happy. Unfortunately, the latter were not

directly involved in this study, but this is an area which might benefit from future research. ✓

(vii) **Improved Marital Relationships**

Four couples reported an improvement in their own relationships which they attributed to use of the scheme. They now had more time together free of the demands of caring and thus, greater opportunity for discussion and relaxation. A few had arranged that, on at least one occasion, when the handicapped child was at the carers, the siblings went to stay with relatives, thus giving parents a complete break from childcare. One mother commented that she and her husband were now able to go out together socially at weekends, adding a dimension to their relationship which had been missing since the child's birth. ✓

(viii) **Summary**

In summary, most parents were able to identify a range of benefits for themselves, the handicapped child and his siblings as a result of using the service. Some were practical in nature - the freedom to pursue new activities and to spend more time with their other children - others had more far-reaching implications for the family's broader coping strategies and quality of life, confirming the scheme's role as a social support capable of effectively reducing stress. Indeed, the greatest number of beneficial effects was reported by those families who had originally presented themselves as under most stress. Their motivation for using the service had also begun to change. It was now seen in preventive terms, rather than as a means of gaining immediate relief from stress. Some change was also found among the low psg families, who originally tended to present their application in terms of the child's best interest.

They too now emphasised their own appreciation of a regular opportunity to relax.

Social Work Support

Nine families in the sample were 'supported' in their use of the scheme by a worker from Share-the-Care. External agencies were responsible for the other six, some of whom were engaged in ongoing casework. The scheme does not officially encourage its own workers to become involved in casework although exceptions to this policy have been made. As Table 5.13 shows, frequency of contact between parents and social workers regarding use of the scheme was varied ('contact' constituting either a phone call or a home visit).

TABLE 5.13 Parents' Reported Frequency of Contact with Social Workers
(regarding use of the scheme)

Frequency of Contact	No. of Families
Frequent (at least once in 6 weeks)	3
Regular but infrequent (once in 2-3 months)	4
Occasional (less than once in 3 months)	8
Total	15

Most parents appeared satisfied with the support they had received, although there were marked differences in perception regarding the appropriate level and nature of that support. Two families from the high psg, as already noted, would have liked more frequent contact particularly during the early stages of the match and of a more directly facilitating nature. They wanted the social worker to act as a catalyst in bringing the two parties together in

order to arrange periods of respite in advance.

Most of the low psg preferred to have less frequent contact with the social worker, nor did they see any need for support in forward planning, one couple having rejected such an offer as too restrictive. This father probably spoke for most when he said:

Once the social worker has made the initial contact, I think they should retire from it. By that I don't mean they should forget about it completely you know. They should monitor the situation, not closely, but on a regular basis for feedback.

Aldgate (1980) has shown that parents differ in the amount of support they need in order to maintain contact with children in foster care. She outlines an important task for social workers in distinguishing between those

who would see the offer of encouragement and other supplementary support services as a further erosion of their responsibilities and those whose life experiences have not equipped them to take this type of initiative. An early appraisal of parental capabilities is essential to the success of the placement.
(p.31)

Although the reasons for placing children in foster care differ significantly from those which apply to respite care, it seems the underlying principles here are similar. It is worth noting that among those who now valued social work support were several parents who had originally expressed negative views of the profession. It is a tribute to the personalities and skills of individual workers that these opinions had changed. One father commented:

Her approach was nice. She is a very approachable lady, extremely nice, caring and she was very competent ... she is a rarity I think.

However, one or two parents were still keen to distance themselves from the need for such support, apparently because of the perceived stigma involved:

Och! I don't have any of these idiots coming here.
No, I don't need anyone at all.

This comment suggests the need for some role clarification; namely, are parents to be treated as clients or as service consumers? Similarly, Bullock et al (1981) distinguish between the social prestige attached to sending children to public school as opposed to the social stigma relating to compulsory admission into care. In the former case, parents have full powers of choice and control, in the latter, they have little or none.

These findings underline the need for regular and frequent monitoring of all matches, although some families will need more active support than others. Several parents had encountered considerable difficulty adjusting to the scheme, yet those who had the most serious problems had not raised the issues with their social workers. This was probably partly at their own choice and partly due to lack of opportunity. Robinson (1986), in the Avon study, found that when matches broke down parents tended to quietly drop out rather than notify the agency of the problem. It has already been found that parents did not always raise difficulties with their carers either.

The findings may be compared to the responses of the 21 'external' professionals who completed postal questionnaires for this study. The majority believed that families do need ongoing support in using the scheme, although at varying levels, depending on individual situations. Some would have liked to offer more frequent

or more casework oriented support than was feasible, due to pressure of statutory work. In a small minority of cases, however, parental need for support and the social work role in providing it were perceived as marginal. Again, this points to a need for some clarification of external workers' role in relation to the scheme.

Overview of the Scheme

(i) Parental Choice and Control

Despite the importance of social work support, parental choice and control were vital elements in making the scheme acceptable and attractive to families. Where parents felt they were not in control, for example, when they felt under pressure to join the scheme against their inclination, outcomes were likely to be poor.

Most respondents reported that they had sufficient power of decision-making within the scheme, contrasting sharply with findings from certain studies of short-term care in residential settings, where parents may feel their rights and responsibilities are eroded by administrative and bureaucratic procedures (Bayley, 1973; Wilkin, 1979; Oswin, 1984). One mother observed of Share-the-Care:

I think it's much better than a formal arrangements whereby you've got a set period laid aside each year and you can't deviate from it. I don't think that would work.

Ease of access, then, and the ability to make their own decisions regarding frequency, timing and length of visits clearly facilitated use of the scheme. The absence of any formal reception into care was greatly valued by parents, as was the corresponding informality of the application and matching procedures. Several references were made to there being 'nothing forced'; building up the match at their own pace helped parents overcome any anxieties.

However, it is worth pointing out that parents in Lothian have less choice of carer than in some other schemes. For example, in Camden, the social worker shows the profiles of several potential carers to each family, who then choose which to meet. With the exception of three parents who applied to Share-the-Care jointly with their future carers, others had little say in the matter, although social workers try to take account of any stated preferences. For some, this represented a real choice:

I wasn't forced into anything. I had choice because I could say 'no'.

For others, it was a case of 'Hobson's choice':

Take it or leave it!

However, as it turned out, all the parents bar one appeared satisfied with their carers, so lack of choice was not generally presented as a problem.

However, one practice which did attract some criticism was that of potential carers first seeing or meeting the child at his school without parents' specific knowledge. This procedure allows the carer to decide against proceeding to the introductory stage, if for any reason she feels unable to take on that particular child. While two parents considered this a sensible arrangement, another resented 'being the last to know about it'; one father disapproved of carers making choices, as he saw it, based on physical appearance, 'like a cattle market'. Both comments arise from parents' dissatisfaction at being excluded from this aspect of the scheme's operation.

Another father made the salient point that, while they held a veto over their individual match, parents lacked control over the wider policies of the scheme, the total package of services for children with disabilities:

The problem with parents with handicapped kids is that they are not involved in the decision-making processes. They are not involved in the formulation of policy ... they know what they need. They know what is best for their children.

His comment suggests there may be a place for parents on some kind of management committee for Share-the-Care.

Nevertheless most of the families rejected the idea of attending some form of Share-the-Care parents group, for two reasons. Some did not perceive themselves as having a need for one (mainly low psg families) while others lacked the time and energy. However, four parents did perceive a useful purpose in sharing experiences with others. Perhaps more would have done so if the question put to them had indicated a specific function for such a group.

Despite the importance which parents clearly attached to choice and control, indications of some difficulty in exercising it (for example, in relation to negotiating respite) have already emerged. Aspects of this process will be explored further in Chapter 6.

(ii) **Suggestions for Change and Development**

Parents were asked if there were any changes or developments they would like to see in the scheme. The majority of answers focussed on expansion of the existing service or the establishment of complementary ones, with few procedural changes being advocated, thus implying general approval of its present operation.

Several people raised the issue of provision for school-leavers. Not only did they fear that their match might come to an end when the child reached 16, they also pointed out that virtually no alternative sources of respite were available, other than institutional, which many preferred to avoid. Again, it was not only respite which concerned parents: the lack of wider services for the post-16 age group was criticised:

The provisions stop at 16 and that is absolutely ridiculous and something is going to have to be done about it, because it really is a major problem.

While care must be taken to avoid creating services for adults which could more appropriately be aimed at children, it seems at least counterproductive for provision to stop at the very age when non-handicapped teenagers are establishing their independence. Six social workers who completed postal questionnaires for this study also referred to this area as a priority for development.

Some parents talked in more general terms about the need to develop the existing scheme, to obtain more funding for it and to publicise it more widely, while a few thought that carers' fees should be increased. Finally, it was suggested that domiciliary care should be made available within the scheme. Similar recommendations for change were made by eight social workers.

(iii) Comparison with other Forms of Respite Care

Only two families reported they were currently using other sources of respite care (namely, maternal grandparents and a hospital). Since the initial interview, five children had been on a short holiday without their parents, run by a school or voluntary organisation, while four had been in hospital for medical reasons.

Five families who had used hospital for respite care in the past, if only on an occasional basis, had not done so since starting Share-the-Care, which all reported they greatly preferred:

There's no comparison. She doesn't think of going to the carers as a punishment or threat.

A crucial factor was that while most parents, as we have seen, had complete trust in the carers and therefore felt able to relax and enjoy their break, this was not true of institutional care:

If it was any other thing, you know, then I would find it difficult, I mean like if he goes into hospital we always find these things very difficult you know, but because I know he ... he's loved and cared for, I'm not at all worried.

Other reasons for preferring family-based care were the absence of institutional trappings, the chance to mix with healthy children rather than sick or convalescing ones, the greater degree of individual attention, the child's enjoyment of the experience and the greater scope it afforded parents to make choices and decisions. By providing good separation experiences, the scheme was perceived as facilitating future independence, whereas unhappy experiences in hospital were said to have made some children fearful of further separations.

One mother made concurrent use of a local hospital for respite: this was the lady who had voiced many dissatisfactions about her match. Her perceptions are in striking contrast to those quoted earlier:

Tony really enjoyed the hospital, lots of children. They all play together. They do a very good service for parents. I wouldn't dream of using it much because they're so busy.

It cannot be assumed, then, that all parents will prefer family-based respite care. Another family who withdrew from the scheme shortly after being matched reverted to their previous routine of using a hospital for respite every second weekend. It is equally important to avoid making parents feel guilty about their choice of services - especially when that choice is limited by scarce provision.

Some parents also found Share-the-Care preferable to having their children stay with friends or relatives, since carers were seen as being more 'objective'. Again it emerged from the initial interviews that some people felt the child's grandparents would not be able to offer help for much longer. Indeed, there was some reduction in assistance from this source since the first interviews. On the other hand, several families who withdrew from the scheme preferred to rely on their informal networks and particularly kin-care. These findings confirm those of the initial interviews that families develop differing types of support network and that arrangements which work well for one may be unsuccessful in another. Clearly, family-based respite care is more acceptable to some families than to others.

Summary and Conclusions

As noted throughout this chapter, the numbers within the consumer sample and the perceived stress subgroupings are very small and can only support tentative conclusions. It should also be borne in mind that families had only been using the service for 6-8 months when these interviews took place and that their periods of respite were relatively short, the bulk of childcare remaining their responsibility. In these circumstances it might be speculated that any changes or benefits arising from use of the scheme are likely to be modest.

The importance was stressed of thorough pre-placement preparation of parents and of well-managed introductions to carers. It emerged that only a minority of parents felt able to initiate arrangements for respite, while those who had difficulty in doing so were likely to explain this in terms of their own feelings about

sharing care. Nearly all expressed great satisfaction with their carers and confidence in the quality of childcare provided: this was a vital element in allowing parents to relax and benefit from the break. At the same time, a majority believed that carers should be seen primarily as the child's special friends, believing that the development of a close relationship between the adults would obstruct the process of sharing care. Far from being a 'gift' to parents, use of the scheme was not always a straightforward matter but raised complex and difficult issues for some parents. Arrangements which work well for one family may be unacceptable to another. Social workers have an important task in distinguishing the level of support appropriate to individual matches, but should be vigilant in monitoring all.

Some marked differences emerged between the perceived stress groupings. Families who had originally presented themselves as under least stress, and who did not express an urgent need for a break, were most likely to be placed on the scheme and had least difficulty in adjusting to use of it. Those experiencing higher levels of stress encountered greater problems, particularly in negotiating respite. Increasing trust in the carers' ability to cope, however, along with active social work support, were helping to overcome such difficulties. These families were likely to report the greatest number of benefits from using the scheme, sometimes with far-reaching effects. Finally, while these findings confirm the scheme's ability to act as an effective social support, indications were found that, in isolated cases, use of the service might create stress by coming into conflict with the nature of parents' existing coping styles.

CHAPTER 6

The Carers

Introduction

Complementary and substitute care of children has been practised in various forms for hundreds of years, although fostering has undergone radical change since the days of the 'poor law apprentice' (George, 1970). Recent innovations which may be seen as precursors of family-based respite care include the emergence of short-term and treatment fostering and the adoption of children with handicaps (Shaw and Hipgrave, 1983). To date, however, relatively little is known about respite carers and the need for more research has been pointed out (Campbell, 1983).

Chapter 6 is concerned with the analysis of data obtained from interviews with 30 carers, half of whom were linked to a child from the consumer sample, and half to children whose families were not otherwise involved in the study. It begins by examining the carers' personal and social characteristics and circumstances and then explores their experiences of caring, particularly in terms of motivation, rewards, dissatisfactions and role perceptions. Where appropriate, the views of the consumer sample will be compared with those of the 15 carers to whom they were matched.

The Personal and Social Characteristics of Carers

(i) District

Twelve carers lived in Edinburgh, seven in West Lothian and eight in Midlothian. Only one family came from East Lothian, corresponding to the poor representation of this division among the parents' samples. Two carers lived in other Regions (Borders and Central) but joined the Lothian scheme because no local equivalents existed at the time.

(ii) **Age and Family Composition**

The sample comprised 25 married couples, one cohabiting couple, a widow, two single women, and, finally, a mother and adult daughter partnership (one widowed, the other, single). For convenience, they will all be referred to as 'the 30 carers' or 'caring couples'.

Table 6.1 indicates the ages of both male and female carers. As a group, they ranged from 26 to 52 (in 1985), the average age of the women being just under 39; of men, 40. These figures are close to those provided by Robinson (1987), regarding carers in Avon, who reports an average age of 39.5 years for women, with the men slightly younger at 36.9 years. A majority of carers in Cornwall were aged between 40 and 49, although, at 14, the sample size was small (Caudrey, 1984).

TABLE 6.1 Ages of Carers (in 1985)

Age group	Women	Men
21-30 years	2	2
31-40 years	13	9
41-50 years	15	14
Over 50 years	1	1
Total	31	26

Excluding the mother/daughter partnership, Tables 6.2 and 6.3 show the number and ages of carers' children. Few were aged under five, probably due to anxieties on the part of parents or professionals that this age group would not react favourably to involvement in the scheme. Similarly, Caudrey notes that few Cornish carers had children younger than five.

TABLE 6.2 Ages of Carers' Children

Age Group	No. of Children
0-5 years	5
6-12 years	26
13-18 years	22
Over 18 years	7
Total	60

TABLE 6.3 Number of Children per Family (at time of application)

No. of Children per Family	Frequency of Incidence
0	3
1	2
2	17
3	4
4	3
Total	60

One couple had a son with multiple handicaps. Five children were adopted or fostered, two of whom had Down's Syndrome. A third was mildly mentally handicapped.

(iii) Socio-economic Status

The sample was almost equally divided between those in manual and non-manual occupational groups, although among the 21 women who were working, a higher proportion fell into the latter category. Only one man was currently unemployed, representing less than 5% of the male sample and corresponding exactly to the figures provided for

the Avon scheme (Robinson, 1987), but falling far below the contemporary rate of male unemployment in Scotland - 19.5% (Employment Gazette, 1985). The unemployed man is classified according to his previous occupation in Table 6.4. It is striking that 58% of female carers had some form of paid employment. In 12 cases, this involved full-time work outside the home, compared to none among the 30 mothers in the sample of applicants. Ten female carers who were not working are excluded from the Table.

TABLE 6.4 Occupational Status of Carers

	Non-manual	Manual	Total
Men	13	13	26
Women	12	9	21
Total	25	22	47

19 carers were owner-occupiers, nine lived in local authority housing and two in tied accommodation. This indicates a relatively affluent sample, since only 36% of the Scottish population were owner-occupiers in 1983 (Office of Population Censuses, 1983).

These findings represent a significant departure from the profile of 'traditional foster parents' described by Fanshel (1966) as likely to have 'working-class' backgrounds and to be 'home-centred'. Findings from other reports indicate that repite carers are more likely to be 'white-collar' rather than manual workers (Bryant, 1984; Fenwick, 1986; Robinson, 1987).

(iv) **Summary**

In summary, most of the carers were married couples, with an average age of 39 to 40. They were almost equally divided between manual and non-manual occupational groups, but two-thirds were owner-occupiers. Over half the women were working while only one man was unemployed. The carers had an average of two children each, most aged over five. In all these respects, they differ significantly from long-term foster parents, described by Triseliotis (1980) as:

Couples mostly in their forties and early fifties at the time of placement; having no children of their own, or their own children beginning to grow away from the family home; holding steady semi-skilled and skilled jobs, and living in council accommodation.
(p.133)

However, the findings are broadly similar to the limited information available about other schemes, although it seems that respite carers elsewhere are more likely to have non-manual occupations.

The Interviews

When these interviews took place, over half the sample had been acting as carers for under a year, although all had done so for at least six months. Only one had been involved in the scheme longer than three years.

Five carers were currently linked to two children, while one family was matched to three (two children from a residential school spent holidays with this family, while a third had been placed in the usual way). In these cases, carers focused on one child for the purpose of the interview. The rest of the sample currently had only one match.

In 20 cases, both husband and wife took part in the interviews, but six male carers did not participate, primarily through their own choice or circumstances. Interviews lasted between 1½ and 2¼ hours. Three were not tape-recorded, at the respondents' request.

Joining the Scheme

(i) Motivation

Fanshel (1966) reports that 'traditional' foster parents do not question their own motivation, but regard fostering as 'a natural kind of action'. The activity was said to satisfy their need to mother and love children, in some cases also to control and direct. 'Pure benevolence' as such was not a motivating factor.

The present sample identified a range of different reasons for joining the scheme, outlined below. These are comparable to Macaskill's findings (1985) about the motivation of families who adopt mentally handicapped children. A significant difference between the two, however, is that loss did not feature among the present sample, presumably reflecting the short-term nature of respite care, as opposed to the permanency of adoption.

TABLE 6.5 Carers' Reported Motivation for Joining the Scheme

Type of Motivation	No. of Carers
'Wanting to give parents a break'	14
Previous positive experience of handicap	12
Time-limited care provided in own home without disruption to family life	12
Prior awareness of parents' need for respite	6
Fondness for children	6
Desire for useful occupation to fill spare time	5
Belief in principle of community care	5
Desire to be of service to others	5
Feeling fortunate in having healthy children	4
To educate own children about handicap	3

Not surprisingly, perhaps, the reason most often cited for joining the scheme was the desire 'to give parents a break', implying that altruism was a significant factor in carers' decisions. When placed alongside other data, however, the simultaneous desire to meet their own needs, along with some qualifications on their commitment to the scheme, suggests otherwise. Taking the data as a whole, three main areas of motivation emerge: a positive commitment to people with mental handicap, expressed by 12 carers as a predominant motivation; the desire to be of service to others, eight carers displaying this as a primary orientation; and a fondness for children, which was the principal motivation for three. However, it is important to stress that the majority of carers expressed a combination of these factors, and in seven cases it was not possible to identify a distinguishing orientation. Having said that, however, each area will now be discussed separately for the sake of clarity.

A positive commitment to people with mental handicap

Twelve carers specifically referred to what might be termed 'previous positive experience of handicap' (Macaskill, 1985) as a reason for joining the scheme, but indications emerged that this was an important factor for many. As Table 6.6 shows, at least one partner in 22 cases had extensive previous contact with people who were mentally handicapped. Almost a quarter of the sample had a handicapped relative, while over half had directly related work experience, past or present. Several, for instance, were currently employed in 'mental handicap' institutions, in special schools or social work departments, their jobs ranging from nursing auxiliary to headteacher. This means that a substantial number of carers were already in close contact with handicapped people in their daily lives

and sometimes the whole family was involved. For example, where the female carer worked at a special school or hospital, her husband and children had visited the establishment, entertained the handicapped children in their own home or even accompanied them on holiday as voluntary helpers. Only one couple were the natural parents of a child with disabilities; the handicapped relative was more likely to be a sibling, aunt or uncle. It is worth noting, however, that one carer whose uncle was handicapped did not believe this factor had influenced her decision to join the scheme. Five carers had more limited contacts; for example, one had some knowledge of a neighbour's handicapped child, while only three had no such experience. Studies of other schemes have also shown that respite carers are likely to have this type of background, although perhaps not to the same extent as has emerged here (Smith and Smith, 1979; Bryant, 1984; Banks, Grizzell and Strettle, 1984).

TABLE 6.6 Carers' Previous Contacts with People with Mental Handicap

Nature of Contact	Number of Caring Couples
Relative plus related work	5
Relative only	2
Related work only	11
Related voluntary work	3
Friends, neighbours	5
Other	1
Not applicable (no contacts)	3

Some carers expressed a strong commitment to the principle of community care, believing that family-based respite was preferable to institutional provision. This included a few who, having worked in residential settings, did not perceive these as an appropriate environment for the care of young children. Others, whose experience

was nearer home, perceived people with mental handicaps as liable to be 'over-protected' by their parents, and therefore likely to benefit from opportunities for increasing independence and integration within the wider community. These carers viewed the scheme as providing them with a means of putting their beliefs into action, beliefs which, in some cases, were very strongly held, as this comment illustrates:

We would like to try and change the world as far as mental handicap is concerned, but we can't, so therefore you just try and do what you can and help one person.

Due to their prior contacts with handicapped people, several carers were already well aware of the pressures faced by many parents and of the latter's need for respite. Thus, their commitment to people with mental handicaps was readily extended to include the latter's families. Four carers had conceived of the idea of offering some form of support to parents before coming across the scheme, demonstrating, as it were, a 'predisposition' to becoming carers.

Clearly, then, a combination of 'personal' and 'professional' concerns were expressed by these carers. While some felt a responsibility to share with others the skills they had amassed over the years, others preferred to present themselves as having nothing 'special' to offer:

We're just an everyday couple, like a lot of everyday couples.

As a group, however, they did not perceive themselves as entering new ground when they joined the scheme. Rather, their decision seemed to represent a logical extension to their previous involvement with, or positive commitment to, people with mental handicap.

The Desire to be of Service to Others

The primary type of motivation expressed by eight carers was the desire to be of service to others (who may therefore be termed 'service-oriented'). Some voiced this objective in a generalised way. Others specifically referred to providing parents with an opportunity for respite. Although this aim clearly played some part in the motivation of many, a significant difference lies in the relative lack of familiarity among this group with people with mental handicap, six of the eight having had no, or only occasional, past contact with handicapped people. It emerged, however, that 12 carers, including six of this group, had been, or were currently, involved in some form of voluntary work, usually outwith the field of disability. Specific areas of activity included the children's panel, the Samaritans, work with psychiatric patients, elderly people and those with alcohol problems. There was evidence that carers who expressed a desire to be of service to others were motivated by a strong sense of social justice and welcomed the scheme as an opportunity to offer practical help at a local level. One woman commented:

I think it is a super scheme. It allows you to do something positive to help people. Often you feel so helpless when you read or hear about people in desperate situations.

Similarly, several carers indicated a sense of social responsibility: since their own lives were relatively comfortable, they believed they should use their advantages to help others:

I thought I was the sort of person who could afford to. Nearly everyone has a good reason not to do it ... I've got time, and space. I can suit myself.

It is worth noting that these carers were among the more affluent in the sample: six of the eight having non-manual occupations and seven being owner-occupiers. Comparable remarks were sometimes made by other carers regarding how 'lucky' they were in having healthy children of their own, again coupled with the desire to help those who were less fortunate in this respect.

These carers did not give the impression that embarking on the scheme was a significant departure from their accustomed activities; for some it seems to have represented an extension of their voluntary work. One couple explained their motivation in these terms:

- (Husband) : To give someone a hand and help them
 enjoy life like we do, as simple as that.
(Wife) : I tend to do things on impulse. I didn't
 stop to analyse why I wanted to do it.
 I wanted to help another mother, so long
 as it didn't disrupt our whole life.

Macaskill (1985) describes adoptive parents of handicapped children as practical people, not given to analytic, conceptual thought. While this may be true of a minority of carers, it did not apply to most. Many were reflective, articulate individuals whose motivation to join the scheme arose, at least partly, as has been seen, from certain firmly held beliefs.

Throughout the sample, the wish to help parents was complemented by a desire among carers to meet their own needs. Several, for example, had spare time on their hands which they wanted to fill in a useful way. Involvement in the scheme may have rescued some from feelings of boredom and loss of purpose:

- I wanted to do something - now that the boys are
growing up. I thought, 'surely there's something I
could do with my time rather than sit here doing
nothing'. I wanted something to enjoy - I didn't
want to go out to work.

Although no carers referred to loss as a motivating factor, in some cases interest in the scheme may have arisen partly from the 'empty nest syndrome' whereby their own family's increasing independence no longer required the same degree of parenting input.

Finally, as already indicated, some carers were looking for an activity which could be performed in their own home, without disrupting family life. In these very practical ways, Share-the-Care was perceived as something which could be readily accommodated within existing routines.

A Fondness for Children

In only three cases was a fondness for children the predominant reason for joining the scheme, but indications emerged that this was an important factor for many carers. All but four were natural parents, while ten had experience of fostering or adoption, either long-term (including three handicapped children) or on an emergency basis. A few carers had worked as childminders or daycarers, while five had been involved in voluntary work with children. These findings point to a commitment to, and fondness for, children among many carers and, since over a third were accustomed to caring for other people's children in their own homes, are further indications that, for most, joining the scheme did not represent a totally new venture. Again, where their own children were accustomed to the presence of others within the household, carers felt reassured that reactions to joining the scheme would be favourable.

More significant, perhaps, is the fact that a further nine carers had considered the possibility of fostering or adoption, but had not pursued it. Several had decided that their current circumstances were unsuitable, either because their own children were

*match motives
2 parents*

very young or else due to pressure of other commitments, particularly at work. Share-the-Care was generally perceived as requiring less commitment, both at an emotional and practical level. Similarly, some couples had expressed firm preferences for a particular 'type' or age group of child, often dictated by the age of their own children. A few carers had been referred to the scheme by fostering liaison workers, because pre-adoption babies were no longer readily available.

Some carers had what might be described as 'child-centred' households, being accustomed to looking after a number of friends' or neighbours' children on a short-term, informal basis. (Two had already cared for their Share-the-Care child in this way and the arrangement was subsequently formalised through the scheme.) In discussing their reasons for joining, several expressed the aim of educating their own children about handicap, believing the latter would benefit from realising that others were less able-bodied than them.

(ii) Hearing about the Scheme

About a third of the sample first heard of the scheme during the course of their work, for example, in special schools or hospitals. It is interesting that publicity material available in these establishments designed to inform parents about the scheme had the unforeseen effect of attracting members of staff to become carers. It has been noted elsewhere that similar schemes have attracted carers through their place of employment (Stevens, 1987; Banks, Grizzell and Strettle, 1984). Another third, as already indicated, came across the scheme as a result of their involvement or interest in fostering, while the remainder had mostly responded to publicity

material, particularly advertisements in a local paper.

It is striking that over two-thirds of the sample did not join the scheme as a result of its active recruitment campaigns. Agency records reveal that, while the initial response to such campaigns may be good, only a small proportion of those who make enquiries eventually become carers. Many drop out, while some are occasionally 'counselled out' by social workers. The agency might therefore benefit from targeting its recruitment efforts at specific places.

(iii) Initial Reactions

It has been suggested that potential carers need repeated exposure to publicity material before acting on it, implying that a protracted, on-going process of decision-making takes place (Bird, 1982). This was not the norm among the present sample, although some couples did delay joining for a year or two because their own children were very young. The majority, however, followed up the idea remarkably soon after hearing of the scheme - 16 within a matter of days and a further seven within six weeks.

On the whole, however, the incentive to become carers was much stronger among women than among men, corresponding to the disproportionate amount of informal care provided by women rather than men (EOC Report, 1982). Most husbands were described as supportive of their wives' desire to join the scheme, if not prepared to be so actively involved, as this woman's comment indicates:

I was more interested, but I was going to have more to do with it. Philip has always been a great back-up.

Six husbands had raised specific objections, usually on the grounds that their wives already had heavy commitments. Most were now said to be fully 'converted' to the scheme, having grown attached

to the handicapped child. Only one was still said to object 'on principle'.

(iv) **Summary and Conclusions**

Most carers had previous experience in at least one of three main areas which appeared to have a significant bearing on their wish to join the scheme. These were: extensive contact with people with mental handicap, voluntary work of a diverse nature and fostering or adoption. Others had considered becoming foster or adoptive parents, but decided against it. Share-the-Care was seen as requiring less commitment, both in practical and emotional terms, and thus less likely to be disruptive of family life. Corresponding to these types of background experience, three main areas of motivation were identified: a commitment to people with mental handicap, the desire to be of service to others ('service-oriented') and a fondness for children ('child-centred'). For many, joining the scheme appeared to represent a logical extension of their previous or existing activities. These findings strongly suggest, firstly, that most of the sample was, in a sense, predisposed to react favourably to the idea of becoming carers; secondly, that it is specific groups within the community who do so; thirdly, that recruitment campaigns should be targeted at places such as hospitals, special schools and social work departments.

Finally, it should be emphasised that the desire to meet their own needs was, quite legitimately, a strong factor in the decision to become carers. Indications also emerged that several wished to draw clear boundaries around their commitment to the scheme, for example, in terms of the time they felt able to give to it and the 'type' of child they were willing to care for. It may be speculated that this

finding would have far-reaching implications for certain aspects of service provision.

The Preparation Sessions

The importance of thorough pre-placement preparation of foster parents has emerged as a key issue in that field of research (Cautley, 1980; Triseliotis, 1986). Berridge and Cleaver (1986), for example, found that fewer breakdowns occurred when couples had received preparatory training.

As outlined in Chapter 1, carers in Lothian are encouraged, rather than obliged, to attend group preparation sessions prior to being matched and among the present sample only half had done so. While most of those who attended no sessions did have previous experience of caring for handicapped children, one or two had not, while others with considerable related experience were nevertheless asked to attend. It seems these decisions were partly governed by practical considerations relating to the timing and locale of sessions. Several carers did not consider any special training to be necessary, believing that their own parenting skills were sufficient qualification for the role. Bryant, Harris and Newton (1980) report similar attitudes among childminders, but the evidence of their study would challenge this view. Those who participated in group preparation had attended between two and eight sessions, the usual number being about four. In five cases, only the female carer had attended, indicating again a greater interest in joining the scheme among women than men. In some cases, children had also been involved.

Six of the fifteen carers perceived the sessions as a useful learning experience; these were people with little background knowledge:

They weren't scared to show you the worst, and I think that's a good thing ... it is better that way than people sort of thinking 'oh, this is easy, it's a doddle' and then once you're all matched up, it is harder, isn't it, to get out.

In general, the more practical aspects were considered most useful, such as a visit to a special school or a talk from established carers about 'real life' situations. Some carers believed they had learnt more from the child's visit than from pre-placement theoretical input. Similar findings were made by Robinson (1986) about the Avon scheme and Macaskill (1985) about adoptive parents of mentally handicapped children. Those with most experience felt they had learnt little during preparation, but several welcomed the opportunity of meeting other new carers.

Suggestions for change and improvement varied considerably, perhaps reflecting more about individuals' own background and interests than about the content of the meetings. Some felt the emphasis was too much on profoundly rather than mildly handicapped children, while others thought the reverse. A few would have liked more information on aspects of practical handling, such as how to bath a physically disabled child, while others recommended more discussion of the emotional issues raised by respite care, such as the attachment between carer and child. Several would have liked a presentation by parents, in order to hear their perspective on the scheme.

Only one couple was highly dissatisfied with their experience of preparation. They had attended a series of sessions run by locally-based social workers, rather than the central team. The staff concerned were said to be insufficiently familiar with the scheme to provide clear information or answer questions raised.

In summary, reactions to group preparation were mixed, reflecting the level of carers' related experience, but on the whole a practical approach was preferred. The implications of these findings for practice are discussed in Chapter 9.

Waiting for a Match

A third of the sample expressed strong dissatisfaction with the length of time they had waited for a match which, in some cases, was several months, although one couple had waited well over a year. Several were particularly galled by the apparent gap between practice and perceived need:

You're hearing on the radio, Radio Forth, big adverts saying 'We're desperate for wee Willie and John to get a place to go to' and you're trekking to a meeting every month and no one's ever saying, 'Well, we've got somebody for you to look after'.

Several commented that they had received little or no information from the agency during this time about the reasons for the delay or the likelihood of finding a match. Some even wondered if they had been forgotten.

contrast
parents

Some carers did not perceive a need for preparation prior to matching; others may not have appreciated the complexity of matching procedures, which may result in delay before a suitable child is found, even while other children remain on the waiting-list. Perhaps these issues should be more clearly explained to carers. Nevertheless, the fact that ten experienced considerable difficulties at this stage, some to the extent that they considered abandoning their application altogether, suggests that the agency should review its practice in this respect. There was no evidence that these carers shared any distinguishing characteristic which contributed to the delay.

Operational Aspects of the Match

Most carers reported that their introductory meetings with parents had been relatively straightforward and successful. The main issues raised correspond to those identified in the previous chapter, such as the importance of the social worker's presence during the initial meeting and the value of the child's family visiting the carers' home. Similarly, data regarding methods of negotiating respite largely confirm the findings of Chapter 5. In only eight of the 30 cases were parents said to take the initiative in asking for breaks, (their carers did not appear to share any distinguishing characteristics) while 11 did so rarely, if ever. Nevertheless, a majority of carers reported that arrangements were operating reasonably well, sometimes because responsibility was shared or a routinised pattern of visits established. Nine carers perceived themselves as responsible for sustaining the match by regularly inviting the child to stay:

In our experience, they never contact us. And no matter how often we say, you know, 'If you're struggling, give us a call' and things like that, they never do. We constantly have to contact them.

It can only be speculated whether parents who are 'constantly contacted' by carers would ever feel under pressure to arrange a break when they did not really want one. Another possible danger of this arrangement is that parents may find themselves accepting whatever package of breaks is offered by their carers, with the unintended result that the visits may be arranged to accommodate carers' needs rather than the parents' - or child's. One carer, for example, who had invited the child to stay on 31 occasions over three years, never did so during school holidays which she wanted to devote

to her own children, yet this was identified by several parents as the time when respite was most needed.

In the majority of cases, however, carers showed great insight into, and understanding of, parents' reservations about sharing care. Several drew on their own experience of parenting, while the behaviour of the handicapped child was sometimes compared to that of their own children. Some carers also drew on their previous experience of caring for - or living with - people with mental handicap and had also shared these with parents, in order to communicate their understanding of the latter's feelings and encourage them to ask for respite when required. Similarly, some parents had apparently shared with carers their reservations about using the scheme. These findings confirm the importance of clear and open communication between both sides in facilitating the process of sharing care.

Eight carers were less than satisfied, however, with the pace of their match. Four reported that progress had been slow and the gaps between visits too long. Conversely, another four were concerned about the risk of over-dependency in parents, a problem also identified by Oswin (1984) in relation to family-based respite care. These carers had been asked to take the child for longer or more frequent periods than they wished and/or at insufficient notice.

A number of factors relating to these matches were examined. Firstly, data obtained from carers and confirmed by agency records echoes the finding of the previous chapter that a typical pattern of visits throughout the sample was one weekend a month. Where carers complained of under-use, the child's visits had indeed occurred less frequently than that, sometimes with long gaps in between, and few

overnight stays. In the four cases where complaints of over-use were made, the child had visited every two or three weeks and was more likely to stay overnight. It must be concluded that although the scheme is designed to be flexible and to meet the differing needs of individual parents, demands above or below the 'norm' of one weekend a month may be experienced as problematic. On the other hand, four other cases of 'under' or 'over' use were identified where no dissatisfaction had been voiced by the carer, indicating that other factors play a mediating role.

Secondly, in two cases where carers perceived themselves as under-used, it is interesting to note that social workers viewed the latter as being a little impatient, and the parents, as cautious and reluctant 'to let go'. Three of these parents fell into the consumer sample: all reported themselves satisfied with the frequency of respite. These conflicting views highlight a potential conflict of need: while carers may wish the match to get under way relatively quickly, particularly if they have experienced some delay before meeting a family, the latter often prefer to proceed gradually, taking time to develop confidence in the situation.

Thirdly, drawing again on data obtained from the consumer sample, complaints of 'over-use' (or abuse) made by carers were partly related to a tendency in some parents to delay contacting their carers until the home situation was highly-stressed, resulting in a last minute phone call requesting help. However, it will be recalled that several parents perceived the availability of emergency help, should the need arise, as a major benefit of Share-the-Care. This again indicates a conflict of understanding regarding the

purpose and function of the scheme which the agency would do well to clarify.

Fourthly, it has already been suggested that some parents are obstructed in their use of the scheme by their perception of carers as altruistically motivated. Bird (1982), evaluating the Pact scheme in York, suggests that parents tend to view carers as 'selfless souls, giving with no return'. Another possible consequence of their perception, not mentioned by Bird, is that one or two parents might feel they could ask a great deal of carers although only one such example was found here. The mother commented:

Mind you, they've got to be very special, to do a thing like that, haven't they ... I don't know if I could do it ... I'm quite sure ... if I wanted them to take Peter for a special time for some special reason, they would put themselves out. I know they would.

Her carers, meanwhile, felt they had virtually been 'press-ganged' into having the child to stay for ten days when his parents announced at short notice they had arranged a foreign holiday. Again, this situation points to the need for good, clear communication between both sides of a match.

The fifth and perhaps most important factor relating to carers' dissatisfaction would seem to be the nature of their commitment to the scheme. It emerged earlier that some carers had placed certain 'qualifications' on their commitment, for example, in terms of the time they were prepared to allocate to caring. Thus, while some appear to have a relatively open-ended perception of their role and are likely to respond sympathetically to 'cries for help', others may feel the need for more clear-cut boundaries and be less flexible as a result. One such carer commented:

X p.596

I felt that I'd gone into it, and I knew what I thought, like I was offering the odd weekend and things, and then all of a sudden here was this woman wanting as much as possible, as often as possible, and I felt the pressure was on.

This theme will be explored further in relation to carers' role perceptions.

In summary, 22 carers were satisfied with the operational aspects of their match. They showed considerable understanding of parents' difficulty in negotiating respite, good communication being an important factor. Nevertheless, carers were more likely than parents to identify some area of difficulty relating to the frequency of the child's visits. These findings highlight a potential conflict of need and perceptions between the two sides, particularly regarding the purpose and function of the scheme. The nature of individual carers' commitment to the scheme is a significant mediating factor, indicating that the agency has an important task in assessing levels of commitment prior to matching and, where possible, linking families and carers whose needs are compatible. It must be recognised, however, that individual need and circumstance are liable to change over time and may be unpredictable. A more satisfactory long-term solution may be for the agency to place more specific requirements on its carers when they first join the scheme.

Carers' Perceptions of Parents

(i) The Nature of the Relationship

Carers were asked how well they knew the child's parents. Four reported knowing them 'very well', 16 'quite well' and a further ten 'not very well', corresponding closely to the pattern which emerged among the consumer sample. Like them, many carers placed particular

emphasis on their relationship with the child, rather than her parents, often describing themselves as her 'aunt and uncle' or 'special friends', while only five of the 30 carers perceived themselves as 'family friends'. Those who entered the scheme with a 'service' motivation appeared to give greater significance to their relationships with the parents than did others, indicating they may have seen their role primarily in terms of helping the latter, rather than becoming attached to the child.

This comment was more typical of the sample:

I don't want to know all about Mrs Harold - I feel what I do have from her is enough for me ... for her to bring Elspeth, to have a coffee, have a chat, just to bring us up-to-date with what's been happening.

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Her remarks indicate that a desirable boundary exists to the parent-carer relationship, although clearly she valued the opportunity for friendly discussion and an exchange of information about the child. Over two-thirds of the sample reported that they regularly talked to parents about the child. A few described their relationship with parents as a 'working' one. They had a clear perception of their role: to offer support to the parents by befriending the child. Several indicated a reluctance to broaden the scope of their involvement, as this man's comment illustrates:

Now we know them quite well but we're not too involved. We're friendly, especially through the children, but we're careful not to get involved in family matters. It would be easy to get sucked in.

Problems had arisen in one case, not because a genuinely close and equable friendship existed between parent and carer, but because there was a clash of perception regarding the nature of their relationship. In this case, as outlined in the previous chapter, the

carer reported that the mother telephoned her every week to discuss her personal problems, such as marital difficulties. The carer found herself increasingly resentful of the other's attempt to engage her at the level of personal friendship and to seek support in areas which the carer considered outwith the scope of her commitment to the scheme. The parent's perception could hardly be more different. She reported knowing the carers:

...Probably as well as anyone knows their carers, probably better. We phone each other for a chat even when the child is not involved.

As mentioned before, two carers who also acted as emergency foster parents were happy to provide personal support to mothers, perceiving it as a valid and legitimate part of their role, illustrating again that much depends on the orientation of individual carers.

Isolated instances were found of some disapproval among carers towards parents. A few believed that parents were not 'making the most' of their breaks, for example, because they did not organise special outings for their other children. Occasionally parents were described as unreliable or disorganised or their child-rearing practices criticised. Such remarks were not common, but stand in sharp contrast to the praise often heaped upon carers by parents. On the whole, however, the relative absence of disapproval can be contrasted to the attitudes of traditional foster parents, who have been described as sometimes holding 'ambivalent or somewhat negative' attitudes towards natural mothers (Cautley, 1980). It might therefore be speculated that carers whose motivation for joining the scheme was predominantly 'child-centred' would be more likely than others to experience difficulties in their relationships with

parents. The numbers in this study are too small to allow for any firm conclusions. However, of the three families originally identified as predominantly 'child-centred', two did express disapproval of parents. No evidence of such attitudes emerged among those with a commitment to people with mental handicap, perhaps reflecting their tendency to adopt a more 'professional' (and thus, non-judgemental) approach, matched in several cases by their own personal relationships with handicapped people.

(ii) **Areas of Perceived Similarity and Differences**

Twelve carers were unable to identify any difference in lifestyle between themselves and the child's parents. Others identified issues related to environment, leisure pursuits, family composition, mobility and domestic routines. Most felt that such differences had little bearing on the match, while perceived similarities were often pointed out. It was noted earlier that carers were often linked to parents from a different social background: this was seldom presented as a problem. In one case, however, carers perceived the parents as more 'intelligent' and articulate than themselves and, as a result, had sometimes felt at a disadvantage when negotiating respite, finding it difficult to assert their own preferences.

All the carers appeared well-informed about the child's familiar routines and adhered to them closely. About half the sample felt their approach to handling the child was broadly similar to that of his parents, although some believed they encouraged the child to be more independent than was the case at home. Nine carers perceived themselves as stricter with the child than were his parents, and several believed that this accounted for some remarkable differences

in the child's behaviour at home and while staying with them. For example, in six cases where persistent sleep disturbance, nocturnal incontinence, prolonged screaming, temper tantrums and/or compulsive eating were said to occur at home, such problems had seldom, if ever, appeared at the carers'. Marked discrepancies between different caregivers' perception of behaviour have been noted elsewhere (Jeffree, Cheseldine and Shorron, 1981; Sutton, 1985). Martindale (1982) suggests that parents may have a lower tolerance and higher expectations of their handicapped child's behaviour than do professional staff and that different behaviours occur in response to different environments, regimes and expectations.

Finding the child was less 'difficult' while staying with them than she apparently was at home created a dilemma for several carers - how far to inform parents of the differences. Most were reluctant to do so, for fear of appearing critical of the latter's ability to cope, undermining their confidence or creating resentment.

It was not clear how far parents were aware that the behaviours which caused so much frustration at home were not exhibited at the carers', but in three cases, the latter were perceived as offering 'better' care, in the sense of being fresher, more energetic and/or firmer.

The Rewards of Caring

Carers identified a range of significant rewards from their role (see Table 6.7). Those which were perceived as bringing direct benefits to the carers, such as the enjoyment derived from the child's visits, may be termed 'carer-focussed'. More vicarious rewards, such as helping parents or making a contribution to community care, may be called 'community'focussed', corresponding to

Fanshel's concept (1966) of the 'private pleasures' and 'social gratifications' of foster parents. In the present sample, the nature of rewards was not linked to the child's age, as in Fanshel's study, but there was some association with degree of handicap. Carers linked to children with profound handicaps did not present their relationship with the child as a reward, but were likely to identify other satisfactions, particularly helping the parents. Again, unlike traditional foster parents, most couples identified both types of reward rather than one. Fanshel also reports that, although few men had initiated the idea of becoming foster parents, most had quickly adapted to their new role and found it more satisfying than they had anticipated. A similar finding was made in the present study. Indeed, in five couples, it appeared to be the male carer who had formed the closer attachment to the child, who in each case was a boy.

TABLE 6.7 Reported Rewards of Caring

Type of Reward	Frequency of Response
Knowing they were helping parents	15
Pleasure derived from child's visits	14
Benefits to own children	14
Attachment to individual child	9
'Personal growth'	7
Feeling needed/occupied	6
Making a contribution to community care	6

Community-focussed Rewards

'Community-focussed' rewards were identified by over half the sample, generally centred on the knowledge that, as a direct result of their contribution, parents were receiving regular respite.

Carers sometimes perceived a difference in parents before and after a weekend break, or over a period of months, and concluded that respite was proving beneficial. This observation was closely connected to the 'carer-focussed' satisfactions of feeling needed and having a sense of purpose. Similarly, perhaps, in over half the cases, the satisfaction of giving parents a break was presented as secondary, as if it were something of a bonus, as this carer's comment illustrates:

[We get] so much pleasure out of Kay. Hopefully, she gets as much pleasure out of being here. It is nice to know her parents are getting a break too.

It may be speculated that while the majority of carers perceived the primary purpose of the scheme in terms of providing parents with an opportunity for respite, as the visits had progressed their relationship with the child had taken on greater significance.

'Community-focussed' rewards were most often mentioned by those who had entered the scheme with a positive commitment to people with mental handicap, by those with experience of working in the field and who had handicapped relatives. There were elements of 'professional' satisfactions among this group, as this comment illustrates:

We are interested in seeing a child who lives at home and the experience of having a child in the family, to have more insight into the problems the parents might have.

Others commented on the satisfaction of providing a family placement for a child who might otherwise be in an institution. However, the majority of this group also referred to satisfactions arising from their fondness of the child. There were fewer references to 'personal growth' or benefits to their own children, perhaps because, as already explained, these families were well used to caring for handicapped people.

Finally, in relation to 'community-focussed' rewards, it might be noted here that, in response to another question, many carers reported that the reactions of their extended family, friends and neighbours to their involvement in the scheme had been largely favourable. Some couples went further, perceiving their involvement in the scheme as a means of educating a wider public about 'mental handicap'.

Carer-focussed Rewards

The 'carer-focussed' rewards most often identified related to the latter's close attachment to the child and/or the enjoyment and pleasure derived from her visits. Not surprisingly, this was mentioned by the three couples who were predominantly 'child-centred' in their motivation for joining the scheme, only one of whom identified any 'community-focussed' rewards, but not by those linked to children with profound handicaps. It would be difficult to exaggerate the fondness with which some carers throughout the sample spoke of the child. Anecdotes were recounted with pride and amusement and shared activities recalled with pleasure. As already noted, many perceived themselves as the child's 'aunt or uncle' or described her as 'part of the family'. Photographs of the child were often displayed in the carers' home. In some cases it seemed that the strength of attachment might create considerable difficulties if and when the match ended, as several carers recognised. However, not one of the eight 'service-oriented' carers identified their relationship with the child as a reward in itself, although two clearly derived pleasure from the visits. Again, this finding suggests that these carers perceived the scheme primarily as a means of helping the parents.

However, the 'service-oriented' carers, along with several others, did identify benefits for their own children, believing the latter had grown more tolerant and caring as a result of the child's visits:

The compassion that [my youngest son] has shown for Mary ... he absolutely adores her. On birthdays, there's cards sent. As soon as [her mother] is away, it's 'Hello, Mary. How are you? Nice to see you'. Big kiss. It really is incredible.

Where the carers' children were young, they were usually described as playing well together: older offspring sometimes assisted in practical care. Indeed, a striking difference between carers' children and the handicapped child's siblings is the greater involvement of the former in helping to feed, dress, wash and generally supervise the child. This may be related to 'novelty appeal' and to the time-limited nature of the carers' involvement. Older teenagers, however, particularly boys, were less involved, often described by their parents as 'doing their own thing'.

Four carers, however, expressed concern that involvement in the scheme was not beneficial to their children. This is discussed in the following section.

Several carers referred to 'personal growth', that is, the development in themselves of qualities such as compassion, patience or even humility. This type of reward appeared to be associated with a sense of gratitude, if not guilt, at carers' relative good fortune: several, for example, referring to their heightened appreciation of having healthy, able-bodied children of their own. Three 'service-oriented' carers who had made similar comments when discussing their motivation for joining the scheme, fell into this group:

I think it's quite good for me to get out and do some of the things I do with Jackie, like swimming or trampolining. I think it's good for me not to get too complacent. I have a very comfortable life - other people don't.

Half a dozen carers specifically stated that they derived satisfaction from the knowledge that they were performing a useful role and felt needed and valued by parents. Many more implied the same satisfaction when they cited appreciative comments or gestures made by parents:

I find it quite rewarding to know that Jenny's mother is so appreciative - she, she can't ... say how much she appreciated what ... the fact that Jenny's happy and I suppose you feel quite good when she is so grateful.

Or, as another carer put it more succinctly:

The natural big-headedness of doing something worthwhile,

indicating again that pure altruism was not a significant characteristic of carers. Blau (1967) points to the inherent rewards of receiving gratitude and social approval:

We would not be human if these advantageous consequences of our good deeds were not important inducements for our doing them.
(p.16)

The Drawbacks of Caring

Almost half the sample had difficulty, when asked, in identifying any drawbacks to the caring role. In most cases, caring was presented as undistruptive to normal family life and the child was said to fit into accustomed routines without difficulty. Several carers were sensitive to the fact that problems might arise for parents if the child always received 'treats' or went on special outings during her visits. Comments like:

She really does whatever we're doing
and

He fits into our routine fine
cropped up often, conveying a sense of the 'everydayness' of caring.

Any practical difficulties which had arisen in relation to aspects of physical care were generally presented as minor. Some level of sleep disturbance was reported in nine cases, (sometimes as isolated incidents) while eight carers referred to medical matters which had been satisfactorily resolved. Such issues were played down in phrases like 'It's not really a problem' (about incontinence), 'She's coming along' (about feeding difficulties) or 'He takes a wee turn, it's no problem' (about epilepsy). One carer, however, was experiencing considerable problems in lifting a child who had become bigger and heavier over the years. In this case the agency's attempt to offer practical help was not perceived as effective and the carer speculated that this issue might eventually force her to withdraw from the match.

However, minor restrictions on their usual activities were perceived as a drawback in eight cases. Some carers felt unable, during the child's visits, to undertake certain tasks which required their undivided attention (such as house decorating), or else, in a more general sense, felt they must keep one weekend a month free of alternative plans. Such restrictions were usually rationalised as an inevitable aspect of the caring role. In three further cases, visits appeared to revolve around the physical care or intensive stimulation of the child, to the extent that domestic tasks, such as cooking and shopping, had to be performed in advance:

We just let everything else go for that time.

The three children concerned presented particular difficulties in relation to feeding and/or prolonged screaming.

Attention has already been paid to the advantages arising from the scheme for carers' own children. In three cases, however, where the latter was aged five or under, concerns were expressed that they were not benefitting from the child's visits, signs of jealousy or rivalry having been noted. Although carers did not regard the matter as a serious problem, the findings do confirm the need for great caution in assessing applications from carers with children under five. Parker (1966) reports an increased risk of fostering breakdowns where foster parents had very young children of their own.

In another case, two teenage girls, described as very attached to the handicapped child, had become upset on a number of occasions by the child's distressed reaction to separation from her mother. Again, social workers must be alert to this danger, although clearly where a child is suffering persistent separation distress, the whole situation needs to be reviewed.

Nine of the twelve carers said to have a particular commitment to people with mental handicap did not report any drawbacks to the caring role, compared with just two of the 'service-oriented' couples. They tended to identify certain aspects of their match as problematic or unrewarding, indicating, again, that they were not altogether happy in their role as carers.

The 'Stress' of Caring

Robinson (1986), evaluating the Avon scheme, originally proposed to make a detailed study of stress among carers, but when no evidence of its incidence was found, this line of enquiry was abandoned. She speculates that carers may have played down any pressure they felt,

perhaps for fear of appearing unable to cope. A somewhat different picture emerges here: over half the sample did admit to an awareness of minor stress or strain. Several, however, emphasised that the demands of caring were a contributory factor rather than a major cause. A number of additional stressors were identified, particularly the presence of other young children. Several carers felt more tired than usual after the child's visits; this was related to the need for constant supervision or disturbed sleep. Six carers identified the child's behaviour as a strain: this included cases of homesickness. On the whole, however, these types of pressure were, again, presented as manageable.

Sutton (1985), comparing the perceptions of nine parents and their carers in Avon, reports that a major difference between the two was that parents experienced caring as considerably more stressful. This Sutton relates to their anxieties about the child's future needs rather than present demands. It seems likely, however, that her finding reflects a fundamental difference between the 'parenting' and 'caring' roles. While carers have chosen the activity and perform it on a time-limited and relatively short-term basis, most parents have little choice in the matter and, for them, the task is long-term and the responsibility total. Both samples were very aware of these differences. Several carers, for example, speculated that they would experience far greater stress if they looked after the child for longer periods:

The key factor is the time limit. We have always got a time limit, and I think you can handle anything, within reason, if you've got a time limit and if you've agreed to take somebody back by 2 o'clock on a Sunday afternoon, and you're having a hard time of it at 9 o'clock on the Sunday morning, then you can always say, 'Well, it's only five hours to go!'

One mother in the consumer sample discussed the same issue from the parents' perspective, making the important point that parents and carers may not differ in their qualities and skills, but in the context of their role.

Withdrawing from the Scheme

Finally, in response to another question, it emerged that 20 carers considered it would be very difficult to withdraw from the scheme, either because they were so fond of the child or else because of anxieties about letting down her parents. Thus, an aspect of family-based respite which is often considered a strength - the close attachment between carer and child - may become a double-edged sword when matches come to an end. Similarly, as Oswin (1984) has pointed out, the 'friendship factor' between parents and carers may develop into a 'dependency factor' from which carers feel there is little escape:

If we just felt we'd had enough, it would be very hard to stop and tell the parents. I think that is the biggest problem in Share-the-Care.

Ten carers believed that 'a good reason' or even 'a justifiable excuse' would be required in order to withdraw from the scheme, while for several the only acceptable means of doing so would be to move out of the area. These findings strongly indicate the need for some form of contract to be drawn up when carers first join the scheme, or enter a match, perhaps requiring a two-year commitment with an option to renew. Such a move would clarify expectations on both sides and set realistic boundaries to the match. This system has in fact been introduced to many matches since the fieldwork period.

Some carers, however, did not regard the prospect of withdrawal from the scheme with such trepidation. These tended to be carers

whose relationships with parents were strained and/or who were not particularly attached to the child. One commented:

Not easy ... even if a child is difficult, although if a carer really can't cope, she should be able to say so and get a different child.

It may be very difficult, however, for carers to admit they do not find the child appealing. Three did, however, express real uncertainty about continuing their commitment to the scheme (and all later withdrew). In these cases, caring was not perceived as meeting their own needs, with the drawbacks apparently outweighing any rewards. Each originally entered the scheme with a predominantly 'service-oriented' motivation. ✓

In summary, carers identified a range of significant rewards from their role and few drawbacks. A combination of 'carer' and 'community-focussed' satisfactions emerged, although the latter tended to be presented as secondary. Caring was generally experienced as non-disruptive to normal family life and the child was said to fit into their usual routines without difficulty. Nevertheless, some source of minor stress or strain was reported by over half the sample, but usually considered manageable because of the time-limited aspect of caring, as opposed to the long-term nature of the parenting role. On the other hand, a majority of carers considered it would be very difficult to withdraw from the scheme, indicating the need for some kind of formal contract.

Those who had entered the scheme with a commitment to people with mental handicap reported a range of personal and 'professional' rewards, encountered fewest drawbacks and no stress. Those who were primarily 'child-centred' reported primarily 'carer-focussed' satisfactions and only minor restrictions. Those with a 'service' ✓

orientation appeared least satisfied and experienced the most drawbacks. They appeared to have made less emotional investment in their role than had others. It seems that the somewhat 'vicarious' reward of helping parents, which was their primary conception of the caring role, was not enough in itself to bring full satisfaction. There were, however, one or two exceptions.

Role Perceptions *re payment.*

The majority of carers perceived their role as a 'caring hobby' (a phrase coined by one of the scheme's social workers) rather than a professional task. On the rate of payment, for example, (currently £9.00 per calendar date of the child's visit) 19 carers perceived this as 'adequate', while ten believed it more than adequate. Only one carer considered the fee insufficient to cover extra expenses incurred through caring for an incontinent child, yet she was one of several who specifically stated they would still act as carers if no payment was involved. A further 15 carers expressed similar attitudes by describing the fee as 'irrelevant' or even voicing some guilt about accepting it:

It's an embarrassment. The form says 'claim' as if it's for expenses, but I don't have any expenses.

Most carers expressing such views could identify no purpose for the payment, a few being actively opposed to it. Rather, they perceived their involvement in the scheme in terms of the personal commitment they had chosen to make to an individual child and were uncomfortable about receiving money for an enjoyable activity which brought them non-material rewards. In one or two cases, the payment was donated to a local charity.

Over half the sample perceived the purpose of the payment as being the reimbursement of expenses, such as outings, breakages, and

extra laundry. In the only case where both partners were unemployed, the following comment was made:

Sometimes you're more out of pocket than others; it depends what you're doing with the child.

It will be recalled that many of these carers were not badly-off and unlikely to be deterred from caring by financial considerations. It is possible, however, that the low level of payment might deter some people on low incomes from joining the scheme, for fear of incurring additional expenditure. Some carers may have played down their appreciation of the fee, in case their motives were misconstrued: it may be significant, then, that 'gratitude for any contributions' was sometimes jokingly expressed.

Paying carers a fee may also serve an important function in formalising - and thus facilitating - care arrangements, as several respondents pointed out:

Shona's mother perhaps wouldn't use the scheme if she thought it was 'charity', if we weren't paid something.

Indeed, considerable evidence has emerged that some parents' difficulty in asking for a break was related to the semi-voluntary status of carers.

In line with their views on payments, the majority of the sample was not attracted by the idea of acting as paid workers, and several expressed opposition to the idea of 'professionalising' the caring role. This perception was partly related to their concept of the scheme as a kind of 'informal caring':

It's not a job at all. It's all part of being neighbourly,

partly to its function as a 'family project' providing a focus for shared activities and partly, again, because the concept of paid employment was considered incompatible with the quality of the relationships involved:

I don't see it as a job - it's more personal than that, although I know childminders get paid.

A similar distinction was drawn by several couples with experience of fostering: foster care was a professional task which took first priority, but Share-the-Care was more akin to an enjoyable leisure pursuit.

As this point indicates, another factor which deterred respondents from considering caring as a part-time job was the time-limited nature of their commitment. Several were attracted to the scheme precisely because of its short-term aspect. Over half the female carers were working and many still had children living at home. Some were concurrently involved in other forms of childcare or voluntary work. For these very practical reasons, they felt unable to take on part-time work, even had they wished to. Similarly, while two-thirds of the sample were willing to extend their commitment to their present match, by taking the child for longer than the recommended six weeks per year if necessary, ten were not prepared to do so and over half the sample was opposed to the idea of being linked to another child so long as their present match continued. In short, a substantial number of carers had drawn firm boundaries around the caring role which they were unwilling to extend:

No, I feel safe within these limits.

We enjoy what we're doing and it's enough.

This was particularly true of those with a 'service' orientation, none of whom wanted a job as part-time carers, while over half were not prepared to extend their commitment to the present match. These attitudes correspond to previous findings which indicate some dissatisfaction among this group and evidence that they were less emotionally involved in their role than many others. Nor would it seem sensible for the agency to pressurise carers to go beyond what they perceived as their limitations.

On the other hand, 11 carers were prepared to consider taking on another child. Three couples appeared to have maintained open, flexible boundaries around their commitment to the scheme:

As long as it fitted in with my family, there would be no limit.

[We'd do it] every weekend, if his mum wanted it.

Not surprisingly, these were mainly 'child-centred' carers or those with a positive commitment to people with mental handicap, both of whom derived considerable 'carer-focussed' satisfactions from their role. One such carer commented:

I feel you have to be emotionally involved, or you're not doing it properly.

Finally, 11 carers did express some interest in the possibility of caring as a part-time (or even full-time) job, although almost half qualified their remarks by pointing out that their present circumstances would not allow it. This group included eight of the 12 carers originally identified as having a positive commitment to handicapped people, who, along with another, all had past or present experience of working in the field. They also tended to make some use of 'professional' concepts when discussing their role, such as the value of maintaining 'working relationships' with parents or the

*Service
child-centred
considerable
1-50
not
CL*

importance of integrating handicapped children into the wider community. The other two carers interested in the possibility of a job were 'child-centred' couples who had originally enquired about fostering. Their interest therefore arose from a different angle. It is worth noting, however, that others who were particularly attached to the child were firmly opposed to the concept of 'professional' carers, perceiving such a development as incompatible with the 'spirit' of the scheme.

Carer Support

The vast majority of carers spoke warmly of the scheme's social workers, for whom many clearly had a high personal regard. Ten carers perceived their social worker as a 'friend', corresponding to the perceptions of traditional foster parents (Fanshel, 1966). It has been suggested that this type of orientation may deter foster parents from raising areas of difficulty with their social workers (George, 1970). No such association was found here. Eleven carers described the social worker primarily as a 'colleague', while the rest perceived him in somewhat more impersonal terms as a source of support or information. Strangely perhaps, no clear association emerged between the orientation of carers, as regards motivation, rewards or role perception, and perceived relationships with social workers.

The quality of support offered to individual matches was considered useful and satisfactory by most. In about half the cases, social workers had helped to resolve difficulties which had arisen, principally in relation to negotiating respite. Other interventions had taken a more practical form, such as the provision of aids or equipment. The knowledge that an approachable person was available

to give guidance if required was a source of reassurance to several carers.

However, a small minority had raised certain problems with their social worker which were not perceived as satisfactorily resolved. Furthermore, in a majority of cases, contact with the social worker, either in person or by telephone, occurred less than every six weeks and sometimes apparently not for months on end. While some carers declared their satisfaction with this level of contact, having no special issues to raise, others did not:

I was shocked at the lack of contact after Day Care.
There's not enough support. He should make regular visits.

Eighteen carers had never initiated such contact themselves, other than for routine matters - including some who were experiencing difficulties in their match. These findings indicate that carers will not necessarily notify the social worker when problems arise, while the latter, having heard nothing to the contrary, may wrongly assume that all is well.

As with the preparation sessions, only half the sample had attended any carers' group meetings. Most who had not done so had never been invited; groups in Mid and East Lothian were yet to be established. Only three carers had chosen not to attend, having neither the time nor inclination to do so. Others (who had attended between one and four meetings) clearly valued the opportunity to gain some sense of group support and identity through sharing their experiences with others. One person described the purpose of the meetings as follows:

To feel part of something - hear what people are doing. We'd met these people in the preparation sessions and it is good to hear how they were getting on.

The main attraction of the groups, then, was contact with other carers: this may be related to feelings of isolation which were expressed by a few. The meetings were seldom perceived as a forum for training input, although one or two carers, again those with a semi-professional orientation, considered this would be a useful development.

In summary, while the majority of carers expressed great satisfaction with their individual social worker, at the same time indications did emerge of a need for more support, primarily in the form of more regular contact with both social worker and fellow-carers. No association was found between the orientation of different carers and their perceptions of carer support.

Summary and Conclusions

Carers were usually married couples with an average age of 39 to 40. They were almost equally divided between manual and non-manual occupational groups, although two-thirds were owner-occupiers and only one man was unemployed. Over half the women were working. In these respects they differ significantly from so-called 'traditional' foster parents. The carers had an average of two children each, most aged over five.

The majority of carers had extensive previous contact with people with mental handicap; almost half had undertaken voluntary work and a third had fostered or adopted children. Others had considered fostering or adoption, but were more attracted by the time-limited nature of Share-the-Care. Most carers expressed a range of motivations for joining the scheme, but 12 were predominantly

motivated by their commitment to people with mental handicap, eight by the desire to be of service to others and three by a fondness for children. However, it should be stressed that the majority of the sample identified a combination of these factors, while the desire to meet their own needs was also an important consideration. The findings suggest that most had a 'predisposition' to becoming carers and that it is specific groups within the community who do so.

Only half the sample had attended group preparation, reactions to which were mixed, reflecting the level of carers' previous experience. On the whole, a practical approach was preferred. One aspect of the scheme which was severely criticised by several was the delay experienced before meeting a family and the lack of communication during that period from the agency.

Twenty-two carers were satisfied with the operational aspects of their match. In only a minority of cases were parents said to initiate arrangements for respite, but most carers showed great insight into, and understanding, of their reluctance to do so. However, several carers complained of being either 'under-used' or 'over-used'. The findings indicate some conflict of need and perception between the two sides, particularly regarding the function and purpose of the scheme.

The majority of carers enjoyed good relationships with parents, although in few cases had close friendships developed. Several preferred a 'friendly but business-like arrangement'. Isolated examples were found of disapproval towards parents. This was partly associated with dramatic differences in the child's behaviour at home and at the carers, which the latter sometimes related to their firmer handling of the child.

Carers reported a variety of significant rewards from their role which were termed 'carer-focussed' and 'community-focussed'. Few drawbacks were identified and any difficulties which had arisen were usually presented as manageable. Many, however, perceived the prospect of withdrawing from the scheme as problematic. 'Service-oriented' carers were less satisfied than others, apparently having made less emotional investment in their role.

The majority of carers perceived the activity as a 'caring hobby' rather than a professional task. They viewed it in terms of their personal commitment to the individual child or as acting in a neighbourly way to her parents. The payment of a fee was often described as 'irrelevant', although some believed it served an important function in formalising the parent-carer relationship. Most carers were prepared to extend their commitment to the present match, but were less keen to take on another concurrently. In many cases there was a sense of clear boundaries delineated around the caring role, particularly among those with a 'service' orientation. Carers who entered the scheme with a positive commitment to people with mental handicap were most likely to be interested in the possibility of a part-time job, having displayed a mixture of 'personal' and 'professional' attitudes towards their activity.

Finally, while most carers clearly had a high personal regard for their individual social worker, indications have emerged throughout the analysis that carers would benefit from a greater degree of support from the agency.

CHAPTER 7

Children and Separation

Introduction

Recent advances in attachment and separation theory have shown that children can benefit from having a variety of stable caregivers, provided the relationships are characterised by attachment, familiarity and responsiveness (Tizard, 1986). Since family-based respite care aims to promote these very qualities and to avoid the more damaging aspects of institutional care, it may be speculated that the risk of 'separation distress' would be greatly reduced or even eliminated.

As noted in Chapter 2, Oswin (1984) identified the existence of widespread 'homesickness' among children using residential short-term care. Her findings are based on a series of lengthy, detailed observations and relate to separations lasting between one night and three months. She is more optimistic about the well-being of children receiving family-based care, (where the length of separations was also likely to be shorter) but as this part of her study is based on interviews with just six 'foster families' and five natural parents, it is hardly representative. Within a sample of 104 children using the Avon Family Support Service, 47% were described by their parents as 'upset at some time about being away from home' (Robinson, 1987). However, the issue of homesickness has been omitted altogether from the evaluative reports of some schemes (Banks, Grizzell and Strettle, 1984; Fenwick, 1986).

An important aim of the present study is to examine the impact of the scheme on the lives of the children using it. Certain findings have already been made in this area, most of which provide

a positive picture of the children's experience. Indications have emerged, however, that children were not always happy at the carers and that distressed reactions to separation did occur in some cases.

Information about 30 children was obtained from their carers and in half these cases, their parents' perceptions were also available. Where possible, additional information was collected from agency records. Unfortunately, however, it was not possible to observe the children in the carers' homes, because the 'observer effect' would have been too pronounced. Broader ranging data relating to the issue of homesickness was obtained from the postal questionnaires completed by 22 professionals who had referred clients to the scheme and, finally, from my own observations arising from attendance at staff meetings and carer preparation groups.

The chapter begins by examining the evidence relating to both positive and disturbed reactions to respite. A number of factors are then explored which may contribute to the incidence of homesickness. Finally attention will be paid to the conflicting interpretations placed on children's behaviour by various respondents and the reasons why such differences should occur.

Positive Reactions to Respite

It was noted in Chapter 5 that over two-thirds of the parents in the consumer sample reported that their children consistently enjoyed their visits to the carers and/or did not appear distressed by the separation involved. It may be worth reproducing here the types of behaviour which were identified by parents as evidence of their children's positive reactions to respite, since these will serve as a useful yardstick by which to measure more disturbed reactions. Parents had noted in their children:

Positive behaviour between visits, such as:

- talking about looking forward to the next visit;
- talking with enjoyment about their experiences at the carers, or about the carers themselves;
- wanting to telephone the carers;
- packing a suitcase before a visit was due.

Positive reaction on seeing the carers, such as:

- smiling and laughing;
- face lighting up/looking excited/clapping hands;
- running up to the carers for a cuddle;
- jumping into the carers' car;
- wanting to play with their children.

Positive reaction on return home, such as:

- being 'full of bounce'/'relaxed and in good shape'/'a little bit riotous';
- eating and sleeping well;
- absence of any disturbed or clinging behaviour.

With three exceptions, data obtained from the carers matched to these children corresponds broadly to the accounts given by their parents. Indeed, two-thirds of the carers' sample reported little or no signs of homesickness in the child. The picture which emerges from carers is largely one of children enjoying themselves for the duration of the visits, but always pleased to be reunited with their families:

She has never cried. She's always been happy, never shy. Maybe she has a few moments of homesickness if we leave her alone too long and she has time to think about it. She's always ecstatically happy to see her mum again.

As this comment indicates, although these children were perceived as well settled at the carers, indications emerged that they were still liable to miss their own families at times, as might be expected of any young child, irrespective of handicap. Thus, the same group of carers reported that the following types of behaviour also occurred from time to time during their visits:

data
1 x
1 x
1 x

- crying for five minutes on arrival or at bedtime;
- asking for 'mum';
- wanting to phone home;
- appearing quiet or withdrawn;
- asking when s/he was going home;
- looking at photographs of his/her own family.

Several commented that the child had been subdued or weepy during their initial visits, or had difficulty sleeping when they first stayed overnight. Some children who generally appeared well settled had shown signs of distress during one visit only.

However, all these behaviours fall well within the range of normal separation reactions for young children and, given that they were not persistent, and that the child could be easily distracted from them, do not constitute any great cause for concern. Rather, they may be seen as underlining the normality of the children's responses to separation and, thus, their similarities to non-handicapped children. Hill (1984) in his study of shared care of under-fives comments:

It was a common observation that children might cry briefly when the parent first left, but then settle happily as they accepted the situation and the carer responded appropriately.
(p.199)

However, it must be noted that data relating to some children indicates an absence of distressed symptoms rather than clear evidence of positive reactions. For example, one carer who had not noticed any signs of homesickness commented:

No night-time disturbance - which is the usual sign of distress with kids.

Similarly perhaps, there were indications that one or two parents who, largely relying on carers' reports, presented the child as well-settled nevertheless harboured a few lingering doubts on the matter:

She cries when we leave but we are told it only last five minutes. It's impossible to tell, but I'm sure, in her own way, she does ... she does miss being at home.

Although the rest of this chapter will concentrate on the incidence of more marked distress, it should be emphasised that the majority of children appeared to be well-settled at the carers. As already discussed in Chapter 5 most parents identified a range of benefits to their children from using the scheme, such as gains in independence and social experience ($N = 10$) or in ability and skills ($N = 6$). Over half perceived the child's experience of respite through Share-the-Care as preferable to that provided within a hospital setting.

Evidence of Marked and Persistent Distress

Among the consumer sample, three parents offered a more qualified account of their children's reactions to separation, indicating that an unsettled period had occurred and/or that the child was ambivalent about the visits. In all three accounts, however, the benefits of respite to both child and family were presented as outweighing any difficulty relating to homesickness and the situation was defined as one which was steadily improving with time. Each parent stressed the importance of continuing the match. For example, the mother of a child who regularly 'regurgitated' during her visits to the carers commented:

As I say, it's gradually getting better and probably it will stop in time. This is why we've got to keep the continuity going for her. I think now she realises that if she does go up to ... [the carers] she will come back here, you know ... but she still doesn't like it.

In these cases it might be said that the level of distress was defined by parents as 'mild/moderate'. A fourth parent, however, perceived her child's distress as sufficiently severe to bring into question the wisdom of pursuing the match. (Indeed, this family later withdrew from the scheme.) In three of these four cases, carers' accounts were broadly similar to that of the parents to whom they were linked.

However, data obtained from carers did^{not} always coincide with that provided by the child's parents. Differences in perception emerged where two parents had described the child as exhibiting positive reactions to respite, allowing for the likelihood that she would miss her parents at times, and in another case where 'mild/moderate' homesickness was reported by the parents. In each case, the carers presented the child as considerably more distressed than did her parents. For example, a carer linked to a 9-year old boy reported frequent difficulties associated with 'hand-overs', as the following example illustrates:

The next time we went to pick him up, he saw us coming up the driveway and he rushed to his dad, and his dad picked him up and he said, 'I want to go to bed'. He obviously thought if he went to bed, he wouldn't have to come away with us. It was terribly sad and in fact we had to carry him out of the house crying.

The boy's mother, however, described his typical response to seeing the carers as follows:

He loves it. He gets very excited, jumps up and down and beams all over and chats ten to the dozen.

In no instance did the parents present the child as more homesick than did carers. The fourth case where perceptions differed sharply was a complex one. While both parties reported the

presence of disturbed behaviour in a 3-year old boy, neither attributed this to homesickness. This case will be discussed in some detail later.

As noted already, about two-thirds of the carers reported either positive reactions to respite or the absence of any symptoms of distress. Six perceived the child as 'mildly or moderately' homesick, in the terms defined above, while a further four had questioned the wisdom of pursuing the match, at least in its present format, so distressed did they perceive the child to be:

Sometimes in the past when I've gone to collect her, she's, she's ... oh, she's screaming that she's not coming 'I'm not going' ... makes me feel awful ... I want it to be nice for her. I don't want to do it if she's not enjoying it.

Indeed, in three cases, alterations had been made to the duration of the visits or the place in which the child was cared for (in her own home, as opposed to the carers').

Because the study's methodology did not involve any observation of the child at the carers' home, there are difficulties involved in making an 'objective assessment' of the incidence or degree of disturbed reactions to separation, particularly where conflicting accounts were given by parent and carer. Nevertheless, it can be said that in 19 cases, no clear evidence of homesickness exists. Many of these children actively showed positive reactions to respite, although they may have missed their parents at times. They will be referred to as the 'non-distressed' group. Ten other children, who were perceived by their carers and/or parents to be showing some level of distress (mild/moderate or severe), will be classified as the 'distressed' group. Added to this number is the case of the 3-year old, mentioned above, who was not seen as homesick by either

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parent or carer. The most useful means of illustrating what is meant by 'distressed behaviour' is to outline the types of reaction which children were reported to show. These may be compared to the positive behaviours already described among the non-distressed group. Evidence was found of:

Disturbed behaviour between visits, such as:

- refusing to return to the carers;
- asking for reassurance that the school bus would not take the child to the carers' house;
- refusing to talk to the carers on the telephone.

Disturbed behaviour on seeing the carers, such as:

- 'her face falls a mile';
- looking reluctant;
- refusing to stay overnight;
- crying and screaming;
- being dragged out of the house screaming;
- wanting to get into bed (to avoid leaving home).

Disturbed behaviour during visits, such as:

- refusal to eat, drink or co-operate in aspects of physical care;
- in a child without speech, constant eye-points to the clock and telephone to indicate her desire to go home;
- temper tantrums;
- prolonged screaming/crying;
- 'trying to put herself into a fit';
- inability to sleep;
- repeatedly saying 'Mum, Dad' for up to three hours;
- regurgitating;
- making himself sick;
- being quiet and withdrawn;
- uninterested in play or other activities;
- constant 'wingeing' and spasm;
- screaming when mother's name is mentioned.

Disturbed reaction on return home, such as:

- clinging to parents' legs;
 - crying;
 - refusal to look at or engage with mother;
 - difficulty in sleeping.
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Such behaviours are similar to those listed by Oswin as indicative of acute homesickness among children using residential short-term care; namely:

Clinging to people, clutching at their legs, repeatedly asking anxious questions such as 'Mummy come?' ... quarrelsomeness, rejection of food and drink, loss of abilities.
(p.183)

It is important to stress that these behaviours occurred repeatedly, persisting over months rather than weeks. In two cases carers were sometimes able to distract the child, so that after a traumatic parting from his parents, the child would appear to recover and enjoy the visits.

Weinraub and Lewis (1977) make an interesting distinction between 'protest' crying evinced by the short-term absence of a familiar adult and the more 'desperate' distress caused by prolonged separation. Bryant, Harris and Newton (1980), on the other hand, suggest that the cessation of 'protest' crying does not necessarily mean the child has recovered, but simply that once mother has left there is little point in continuing to protest.

On the whole, however, despite the considerable patience and resourcefulness evidently shown by carers, it proved extremely difficult to distract the children from their distress. One carer, for example, gave the following account of a sleepless night with a 2-year old:

I eventually got her to sleep at 9.40 and I went to my bed and she was awake at 10.30 and (my husband) nursed her until 12.30 and I got up at 12.30 and nursed her until 3.20 and I eventually got her to sleep. She and I both went to bed and she awakened at 5 o'clock and he got up at 5 o'clock and nursed her ... it was a nightmare.

For the most part, these behaviours did not occur at home. It would seem most important when the child does exhibit disturbed behaviour at the carers to ascertain whether a similar pattern was emerging in other settings. Thus, one boy who had originally settled well later entered a period of crying at the carers. It emerged that the same behaviour was occurring at home and thought to stem from factors quite unconnected to respite care. There is no reason therefore to interpret this as homesickness. The girl who regularly 'regurgitated' whilst staying at the carers, also did so at school during, and for about a week, after the visits, but did not do so at home, while a 3-year old boy was said to make himself sick at the carers and during periods of respite in hospital, but again, not at home. It may therefore be inferred that these behaviours were related to separation. On the other hand, one child with a disturbed sleep pattern would wander around the house at night both at home and at the carers, while a 6-year old boy always screamed for a prolonged period at bedtime. Given that these behaviours appeared in both settings, they do not appear to be indicative of distress. More commonly, as noted in Chapter 6, children showed dramatic improvements in behaviour or abilities while at the carers: several who were incontinent, slept badly or had screaming fits at home did not do so during the visits. In short, it is important to examine the circumstances in which behaviours appear in order to ascertain their significance.

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Contributory Factors

A number of factors relating to agency practice, child and family were examined in order to identify any variables which may contribute to or exacerbate the incidence of homesickness. The 11

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children who appeared to show some level of distress were compared to the group of 19 who apparently did not. It should be noted, however, that the numbers concerned are relatively small and that little information was available about the 15 families outwith the consumer sample.

The total sample contained 13 boys and 15 girls, while the 'distressed group' comprised 4 boys and 7 girls, indicating that the latter may be slightly more at risk. Hill (1984) made a similar finding and speculates that boys may be more encouraged than girls to gain a degree of independence from an early age.

Homesickness affected children of all levels of ability. An example can be given of a 4-year old girl with a profound handicap. Having been collected from her home by the carers, this child would start to cry as they drove away from her street. She continued to do so throughout the visits which never lasted more than a few hours. On the way back, when they reached the traffic lights at the end of her road, the crying stopped. Her carer commented:

It's a high-wingeing sort of peculiar sound and the constant spasm ... I don't think she understands any of it at all, other than she's not in the place where she's secure. That's as far as the understanding goes.

Similarly, agency records indicate:

In spite of her very profound handicap, Mary demonstrates real feelings of separation anxiety when parted from her mum.

Discussing the placement in short-term care of children with this level of disability, Oswin (1984) writes:

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It is extremely unjust to assume that because they are blind and deaf and immobile they will be unaffected by the loss of familiar surroundings and people. They may suffer immense grief and bereavement, which is made worse because they lack the hearing, sight, language and mobility which could give them clues as to what has happened. Removal to a strange environment will be a total dislocation of the profoundly handicapped child's world because it deprives him of all the detailed points of reference which mean security.
(p.177)

At the other end of the scale, a mother who perceived her daughter as acutely distressed, commented that the child's ability to understand certain implications of respite care made the situation more painful for all concerned.

Symptoms of distress were also found across a wide age range. The sample contained 11 children aged 4 or under when they joined the scheme, five of whom appeared to be homesick, while six did not. Nevertheless, it may be noted that, during the fieldwork period, the agency appeared to lack any consistent policy about accepting very young children on the scheme, which might take account of their increased vulnerability to separation distress. Professionals who completed the postal questionnaire were asked how they would respond to parents who applied to Share-the-Care for a child aged under five. Twelve out of 20 indicated a need for caution, for consideration of alternative options and for careful preparation and monitoring. A typical response would be:

Check out the home situation - bonding/reasoning behind applying. Take it cautiously and look at each individual's circumstances. I would not reject them without good reason.

Eight professionals, however, apparently saw no need to distinguish between under-fives and any other age group:

What's the problem?

Not any differently to parents of other children.

The younger, the better.

Again, at the other end of the scale, were four girls aged between 11 and 14. It is possible that their current developmental stage contributed to their weepy or withdrawn behaviour. The mother of one commented:

I can't understand why she kept crying and she was very unsettled. It may just be, I mean, she's maybe just going through a bad phase at the moment. She's very clingy. She's not pleased if I go out.

Pre-placement Preparation of Children

The importance of a gradual preparation for children before they are left in the care of child-minders or day nurseries has been noted elsewhere (Bryant, Harris and Newton, 1980; Mayall and Petrie, 1983). Robinson (1987), linking the incidence of homesickness among children using the Avon Family Support Service to a lack of adequate preparation, comments:

The number and frequency of visits prior to [overnight] stays appeared to be largely a matter for parental discretion.
(p.266)

Although children in Lothian had, on average, a higher number of introductory 'day-time' visits than did their Avon counterparts, it may be argued that some would have benefitted from further visits before staying overnight. Most had two or three introductory visits, but three children had stayed overnight on the first occasion they went to the carers' house, in one case, this visit lasting for ten days. A further seven children had stayed overnight after only one previous visit unaccompanied by their parents. On the other hand,

however, no obvious link was found between levels of preparation and reports of homesickness. Among those classified as showing signs of distress, five children had three or more preparatory visits, three had two such visits, and a further three had one. Nor were those who stayed overnight on their first visit perceived as upset by their carers.

Response
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Nevertheless, there is little doubt that the quality of preparation offered to children was very variable. Indeed, during the fieldwork period, the agency, again, appeared to lack any clear or consistent policy in this regard. Social workers who completed the postal questionnaire for this study were asked what kind of preparation was given to the children whom they had referred. Most stressed the importance of a gradual build-up of visits and the value of talking to the child where possible. A few, however, commented that this was mainly left to the parents and one felt it was an aspect of the scheme which could be improved. One or two, however, considered preparation to be unnecessary or irrelevant to children with severe handicaps.

Parents were also asked how they had first explained the visits to the child. Over half the consumer sample had presented them as a 'treat', describing the carers as the child's 'special friends'. For example, in the case of a 13-year old girl with relatively good comprehension, her mother reported:

I just told her that we were going to see the Munro's and if she liked them, and if she liked the house, she could go and stay with them for weekends, instead of [the hospital] which was quite crafty, because putting it as an alternative to [the hospital] means she says 'Yes' to anything!

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A child with more limited comprehension had been given a simple message in Makaton about 'one sleep at Ann's house'. In five cases, however, no preparation of this kind had been undertaken due to the child's young age and/or profound handicap.

Length, Frequency and Timing of Visits

Data relating to the length, frequency and timing of visits was examined in order to ascertain any association which might exist with homesickness. Taken as separate variables, none produced conclusive results. For example, 11 carers reported that the child had on occasion stayed with them for a week or longer. Four were classified as showing signs of distress. There were indications that frequency might be significant in relation to overnight stays. The three children in the sample who stayed with their carers at least once a fortnight had each shown a disturbed reaction, but this was not so in the case of a boy who spent every second Saturday at his carers, but did not stay overnight. One or two 'distressed' children had joined the scheme shortly before or after another event in their lives which might be expected to unsettle them. A 9-year old girl, for example, who had been an only child, accustomed to enjoying her parents' undivided attention, began visiting the carers just four months prior to the birth of a baby sister, following which she showed considerable resistance to the visits. Her mother commented:

Anna's not been so good about it since I had the baby ...
I think she was frightened to leave the baby, and it
maybe not be here when she came back ... when the baby
came, I think she thought she was getting pushed out.

distressed - 10/7/84
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Taking the data overall, it would seem to be a combination of factors relating to the length, frequency and timing of visits which contributes to distress in a child. Thus in the case quoted above, the girl was able to cope with an afternoon visit, but not an overnight stay. In order to 'prepare' another child for a 10-day stay at the carers, when her mother had to go to England, the following pattern of visits took place:

November 10 : child's first overnight stay at carers;
11 - 13 : child at home;
14 : child at carers;
15 : child at home;
16 - 17 : child at carers;
18 - 20 : child at home;
21 - 22 : child at carers;
23 : child at home;
24 : child at carers;
25 - 28 : child at home;
30 -
December 8 : child at carers;
9 : child at home.

She then had no further visits to the carers until February 16.

Not surprisingly, during this highly unsettled period, the girl showed considerable signs of distress, including screaming, head-banging and regurgitation.

Another child from this group spent 10 days at the carers after only one previous overnight stay, while an 18-month old baby's first experience of staying at the carers lasted four nights. Although the numbers are small, these findings do indicate a need for close monitoring of the matches, to ensure that any instance of under-use, over-use or a very irregular pattern of visits is not causing distress to the child, particularly among the under-five age group.

Previous Separation Experiences

An important determinant of the impact of separation on children using day-care is the nature of previous such separations (Provence, Naylor and Patterson, 1977). Unfortunately, data pertaining to this subject is available only for 15 children from the consumer sample, seven of whom were classified as homesick. During their initial interviews, parents had been asked a number of questions relating to their children's experiences of staying away from home prior to joining the scheme. It seems that those who were showing some signs of distress were likely to have had a higher number of admissions to hospital or institutional care, to have experienced longer periods of separation from their parents and to have had shown poor reactions to institutional care, whether their admissions had been for medical or 'social' reasons. One mother, for example, commented:

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[The hospital] was a tremendously awful experience for Ruth. She was so frightened after that and she still ... to her, going away from home is a punishment. If Mummy's not going, then its a punishment.

Similarly, parents of the distressed children tended to give more qualified accounts than did others of their own reactions to being separated from the child in the past, some expressing mixed feelings of relief and guilt. Although there were clear exceptions within both groups, the evidence does suggest that the nature of previous separation experiences, particularly within hospitals, may have played some part in determining children's current responses to family-based respite care.

From these findings, it might be expected that a clear link would emerge between parental attitudes towards sharing care and the incidence of homesickness, but this was not so. A more significant single factor was probably the nature of the mother-child attachment,

an explanation offered by a number of parents and carers, and sometimes echoed in agency casenotes. Close examination of the data indicates that ten children were described by either parent, carer and/or social worker as being particularly attached to their mother or, in one case, father, all of whom were classified as homesick. One mother for example accounted for her children's behaviour at the carers in the following way:

I think myself it is just being ... its Susan and myself, you know, I mean, maybe we're just, you know, we've just got too close, which I think in a way is a bad thing. I don't know what we're going to do with her.

The only similar remark made about a child from the 'non-distressed' group was that one girl was:

Very involved with her family.

These findings provide a strong argument for the availability of some form of respite care from an early age, provided that certain important safeguards are made in the placement of very young children.

It has been noted elsewhere that events leading up to separation, particularly family conflict or stress, are likely to evince disturbed reactions in young children (Provence, Naylor and Patterson, 1977). No significant differences were found, however, between the stress groupings, nor were children more likely to react badly to separation in those cases where parents tended to delay contacting the carers until the home situation had become tense.

Finally, a number of carer-related factors were examined, such as motivation, previous contact with handicapped children and experience of fostering or adoption. None of these appeared to be associated with the incidence of homesickness.

In summary, homesickness was found to affect a range of children, irrespective of age, gender or level of ability. At the same time, it was speculated that girls rather than boys and under-fives rather than other age groups, may be more at risk. While the length, frequency and timing of visits may not in themselves have contributed to the incidence of distress, it was suggested that a combination of these factors may be significant, especially in relation to the preparation of children. Indeed, the quality of preparation was found to be variable with no special provision being made in the placement of the under-fives. Indications emerged that the nature of children's previous separation experiences and their attachment to their parents, especially their mothers, were significant factors in determining their current responses to separation. Finally, however, it should be stressed that no single variable emerged as critical but rather, where homesickness had occurred, it was a combination of different factors which affected outcomes. It may be speculated that aspects of the child's psychological make-up and personality are also important.

Differences in Perception and Interpretation

It was noted earlier that, in four cases, parents and carers differed sharply in their perceptions of the child's reaction to respite. Further examination of the data reveals that, while some parents and carers were considerably anxious about what they saw as the child's distress, there was a tendency among others to play down the impact or extent of certain behaviours or to avoid interpreting these as symptomatic of distress. Again, this finding may be related to a failure on the part of the agency to identify homesickness as a widespread issue and cause for concern. It may be useful to begin by

end.

offering a detailed example of one case in which apparent signs of distress went unrecognised. This is the example already referred to concerning a 3 year old boy named Tom. During the course of the interview with his carer, the following points emerged about Tom's behaviour during periods of respite:

- that he cried and screamed on arrival, 'for five minutes or a wee bit longer';
- that he had twice awakened screaming during the night;
- that he sometimes screamed when people left the house or the room, or when the carers made reference to his mother;
- that he frequently made himself sick;
- that he was otherwise rather quiet and withdrawn during the visits.

The following points emerged about the circumstances surrounding this match, which had been operating for eight months:

- that Tom was 3½ when it began;
- that he had only 2 daytime visits (one accompanied by his mother) before staying overnight;
- that on the first two occasions when he stayed alone, his mother had left him when he had fallen asleep during the afternoon;
- that he spent every other weekend at the carers, from Saturday to Sunday afternoon;
- that he had started school within six weeks of joining Share-the-Care;
- that he had repeated hospital admissions, during which he again made himself sick;
- that he was said to have a 'mental age' of about 9 months and no concept of time.

The carers expressed some concern about Tom's age and the inadequate preparation prior to his first overnight stay. They had resisted what they saw as his mother's hints that they might take Tom more often, thinking that more frequent separations would not be good for him. However, they insisted that Tom was neither homesick nor distressed, but explained his behaviour in the following ways:

I don't think he's actually upset, he's just doing it as a habit ... I think it's just the way he is, it's not like a normal thing, it's a behaviour thing. It's not a, a homesickness, it's not, because it would have stopped by now. It's difficult to explain. A lot of things upset kids like that. They're not like normal children, you see. I think he does it for attention.

This couple had responded to Tom's crying on arrival by trying out various different methods of hand-over, none of which had effected any change in his reactions; to his self-induced vomiting, with 'strictness', and to his screaming in the middle of the night by shaking, and then cuddling him. This had proved effective.

Although the carers had informed his mother about the vomiting and she obviously witnessed his distress at hand-over, they had not discussed the situation with their social worker, perhaps partly because he had not visited them for several months.

Tom's mother also perceived him as unhappy at the carers and provided some additional evidence:

If I'm sitting there, he will cling to my knees, cling like this, it's horrible to see ... clinging. I have never seen him like that. It's only there he does it ... As soon as I take him to [the carers] he is crying before I get him out of the car. He starts crying when I come back.

She did not, however, link Tom's behaviour to separation nor homesickness, but to boredom and lack of stimulation at the carers. She repeatedly stated this view:

Some children when they are younger, they don't sleep when they go away from you, but he does. It's possibly boredom a lot of it, he gets bored very easily, if he's not got something to occupy him. He wouldn't be upset going somewhere he liked. It's only because there is nothing for him to do when he gets there, I think, that he gets upset.

Tom's mother had not informed her social worker about her worries, having apparently had no contact with her for over eight months. She commented:

I have never seen anyone to say anything to, except you.

The Parents

Bryant, Harris and Newton (1980) suggest that some mothers using childminders may have to 'defend themselves against the painful knowledge' of their children's unhappiness. It may be speculated that the same process can occur in relation to family-based respite care. Indeed, evidence emerged that some parents took evasive action in order to avoid witnessing their child's distress. One couple, for example, failed to tell their son in advance when he would be going to stay with his carers. Indeed, they sometimes attempted to 'smuggle' a suitcase onto the school bus in the morning. To the child's dismay, he would then be collected from school in the afternoon by his carers, spending the weekend with them when he had been expecting to go home as usual. Nor did his mother always inform the child when the carers were due to collect him from the family home, because she found it too painful to watch his disturbed reaction to the prospect of separation. Provence, Naylor and Patterson (1977) emphasise the importance of parents 'saying a proper good-bye' to their children while Fahlberg (1981) points out that open, active transfer of parenting helps to reduce distress. In this case, the boy's carers were themselves anxious and upset about his distressed reactions to respite, while his mother reported in interview that no homesickness had occurred.

A similar point emerges in the case of another couple who, according to their carers, arranged for their daughter to travel to

the carers' house by the school transport, in order to avoid witnessing the distress she always showed when they took her there themselves. Oswin (1984) travelled with children on the school bus as it delivered them to residential short-term care facilities. She comments on the bemused and distressed reactions of children as the bus drove beyond their road-end 'and took them elsewhere'. While it may be questioned whether arrangements made to reduce parents' anxieties are likely to have the same effect upon that of their children, these examples illustrate a dilemma which may be faced by many parents using short-term care. On the one hand, they may find it too painful to confront their child's homesickness. On the other, they may feel a great need for regular respite, and are reluctant to cancel or change existing arrangements. Lack of alternative services means that few other sources of respite may be available, other than institutional care, which many prefer not to use. Thus, parents may be left in the unenviable position of 'weighing up' the possible harm caused to their child through persistent homesickness against the potential damage done to the whole family if no respite is available. This concern was also voiced by a number of carers:

If Tony is a well-loved, and cared for, happy child, and a healthy child, you know, I mean, this sort of intermittent distress, you know, is it so bad, if it means he can stay in a happy home situation a bit longer?

The Carers

In order to avoid causing anxiety to parents or spoiling their enjoyment of respite, carers may decide against alerting them to the child's homesickness. In one or two cases, parents expressed their belief that, due to the absence of certain behaviours at the carers, such as sleeplessness or screaming, the child was well settled,

whereas data obtained from carers reveals that these very behaviours had occurred. For similar reasons, two children were discouraged from phoning home during the visits, although they wished to do so. It is now generally accepted, however, that opportunities to communicate with parents during periods of separation help to reduce homesickness (Provence, Naylor and Patterson, 1977). More commonly, it seemed that carers gave parents an outline of the behaviour but did not make explicit its degree or persistence. It will be recalled that carers appeared to play down any practical difficulties which had occurred in relation to their task; it may be that a similar perspective is being applied here. A tendency was also identified among some carers to avoid interpreting the behaviours as indicative of distress, but to suggest alternative explanations. As indicated above, for example, Tom's carers perceived his screaming, crying and self-induced vomiting as an inherent aspect of his handicap, rather than a toddler's natural reaction to repeated and ill-prepared separation from his mother. In other cases, similar behaviours were interpreted on occasion as attention-seeking ('a bit of the dramatics'), as confused and insignificant ('saying one thing and meaning another') or manipulative. While there is nothing unusual about young children acting in these ways from time to time, this does not preclude the possibility that they did so as an expression of homesickness.

Conversely, a few carers perceived children with severe or profound handicaps as so unaware of their surroundings and/or caregivers as to be 'immune from homesickness', as the following comments illustrate:

I don't think these kids realised their environment. I think they accept whatever environment they're put into after a given period of time, as long as they're well cared for and looked after.

As long as she feels well cared for and comfortable and in a happy atmosphere, I don't think it affects her all that much.

Not surprisingly, these carers reported that no signs of homesickness had occurred. Similarly, perhaps, a carer matched to a 2 year old considered the child 'too young to feel homesick'. In the light of these remarks, and given the findings already made about the presence of homesickness both in children with profound handicaps and in under-fives, it can only be speculated whether distress was more widespread than the data reveals.

Bryant, Harris and Newton (1980) report that childminders find it very distressing to look after unhappy children. Carers who did perceive the child as upset usually experienced considerable anguish themselves and, in at least one case, their own children were similarly affected. One carer remarked:

I was just about at the stage where I thought, 'Well, I'm going to have to stop this for my own mental health', because it was getting such a strain, you know, trying to coax her all the time to have a good time.

The dilemma may have been accentuated where carers were particularly attached to the child, and loathe to suggest any change in existing arrangements which would reduce the visits or bring them to an end. Finally, it may be speculated that carers would have been readier to identify, report and respond appropriately to signs of homesickness had the agency itself identified it as an issue of potential relevance to all matches, and prepared carers accordingly in advance. In the absence of such input, however, individual carers

may have felt discouraged from raising the matter with their social worker, for fear of appearing unable to cope. Returning for a moment to Tom's carer, it may be significant that she declared a desire to show her social worker how good a carer she was.

The Agency

In a report to the Lothian Region's Social Work committee the co-ordinator of Share-the-Care wrote:

The children are children first and handicapped second.
(Taylor, 1984, p.5)

It is a generally accepted policy that practice should be guided at all times by normal childcare considerations.

In January and February 1984, I attended a full series of carer preparation groups, during which the issues of separation, homesickness and distress were not raised. There was reference to, but little detailed discussion of, parents' feelings about 'letting go'. Between November 1983 and June 1985, I attended two carers' group meetings, two informal steering groups, four meetings of social work area teams involved in the scheme, four presentations given by project workers, seven Share-the-Care staff meetings and two field services management groups. According to the fieldwork notes taken during these meetings, the issue was mentioned on two occasions: once as an isolated example of a child who was acutely, and conspicuously, homesick and once in relation to profoundly handicapped children, when a social worker outwith the team commented that such children are impervious to separations.

In his report to the social work committee, the scheme co-ordinator also commented:

Children receive one-to-one attention and are not distressed in placement - they usually look forward to it.
(p.15)

Examination of agency records also suggests that issues relating to homesickness were not a major priority in social workers' thinking during this period. Casenotes for four of the children who appeared to be severely distressed carry no reference to the matter. In other cases, where the difficulty was recognised, it seems that it was sometimes left up to parents and carers to decide whether the match should continue. Alternatively, a decision to proceed was made on the grounds either that respite was beneficial to the parents, or that the carer was prepared to cope with the symptoms of distress. Again, these points illustrate the very real difficulty faced by social workers in measuring the child's disturbed reaction to the visits against the parents' need for, and perhaps insistence on having, periods of respite. In some cases, social workers may believe that the withdrawal of Share-the-Care would eventually result in an admission to long-term care.

Professionals who completed the postal questionnaire were asked if they thought children ever felt homesick while at the carers. About a third replied in the affirmative, although two reported that children only became distressed during longer visits. A few social workers considered it would be difficult to assess the presence of homesickness, whilst six did not perceive the child as distressed, including three whose young clients have been classified as acutely homesick.

Many social workers pointed out that the scheme provided the children with a positive separation experience:

Separating from their own family for a good family experience, as opposed to going into hospital; developing new relationships.

10/11

On the other hand, one or two did not believe the scheme made much difference to children:

Very little, in that children are so severely handicapped their level of awareness is minimal.

In summary, despite the widespread existence of certain disturbed behaviours in the child which, it would appear, were largely indicative of homesickness, a tendency was found among several respondents to play down the extent and impact of such behaviours or to avoid interpreting them as symptomatic of distress. At the same time, many parents and carers clearly found it very painful to witness the child's unhappiness. It seems the agency itself failed to identify homesickness as an issue of potential relevance throughout the scheme. However, if the same childcare considerations were consistently applied here as would be expected when dealing with non-handicapped young children, the incidence of homesickness might have been considerably reduced.

Summary and Conclusions

About two-thirds of carers (N = 30) and parents (N = 15) reported that the children had reacted positively to the experience of respite and most were able to cite specific behaviours as evidence. In some cases, however, their judgement was based on an absence of distressed behaviour rather than clear evidence of the child's enjoyment. Evidence emerged that a group of 11 children had undergone a period of more marked distress which in some cases was proving persistent and severe. For the most part, the behaviours which appeared indicative of distress did not occur at home.

A variety of factors were considered which might have contributed to the incidence of homesickness but no single one emerged as critical. However the quality of pre-placement preparation of children was found to be very variable. Indeed, the scheme lacked any clear or consistent policy in this area, as it did also in relation to the placement of under-fives. On the other hand, it will be recalled that several families in the high psg group had children aged seven or under, indicating a real need for respite from an early age. Indications emerged that problems may arise for children who are very closely attached to their mothers or whose previous experiences of separation have been poor.

Nevertheless, a tendency was found among some respondents, firstly to play down the extent or impact of certain behaviours which appeared indicative of distress and, secondly, to avoid putting such an interpretation on these behaviours but to offer alternative explanations, focussing either on deliberate misbehaviour or the presence of a handicap. Conversely, some carers perceived children with severe or profound handicaps as so unaware of their surroundings as to be incapable of feeling homesickness, a view which, unfortunately, was echoed by a small minority of locally-based social workers. The evidence of this study shows this to be an alarming and dangerous misconception. Other respondents, however, perceived the child as suffering considerable distress as a result of separation which, in turn, caused them considerable anguish. Finally, these findings must be related to an apparent failure on the part of the agency, during the fieldwork period, to identify homesickness as a widespread issue and cause for concern.

Finally, it should be repeated that, even given good preparation, occasional signs of homesickness is a natural, even a healthy, reaction among children. Bryant, Harris and Newton comment with concern about children who appear very 'good', quiet and passive at their childminders, suggesting this rather unnatural behaviour is indicative of underlying unhappiness.

CHAPTER 8

Part I - Families who Wait

Part II - Families who Withdraw

Introduction

Only half the original sample of 30 applicants was successfully matched to carers by the time the follow-up interviews took place. The fact that a further 15 families were not is a significant - and unexpected - finding. Five families remained on the scheme's waiting-list throughout the fieldwork period. A further nine withdrew from the scheme, either before or after being linked to carers. Follow-up interviews were conducted with both groups in order to explore why these outcomes should occur and what sense was made of them by parents. Part I of this chapter is concerned with those on the waiting-list, Part II, those who withdrew.

Part I - Families who Wait

'Hard-to-Place' Children

It might be speculated that some families remained on the waiting-list indefinitely because their children were, for some reason, 'hard-to-place'. Because the present sample size is so small, (N=5) however, it may be useful to begin by opening out the discussion and exploring the concept of 'hard-to-place' from a broader perspective. This can be done, firstly, by examining the characteristics of a larger group of children who had waited many months for carers, secondly, by examining the agency's understanding of 'hard-to-place' and, thirdly, by looking at the types of children which carers had in mind when they applied to the scheme.

Firstly, then, information was collected from agency records about a group of 14 children who had remained on the scheme's

waiting-list for 18 months or longer. These children and their families are not involved in the study in any other way. Data gathered about them was compared with the findings already made about the 15 children in the consumer sample, who were successfully matched.

Indications emerged that girls were more likely to be matched than boys, perhaps because they are seen as more manageable. The most important factor, however, was age. Those in the consumer sample were noticeably younger as a group than those who waited over 18 months, nine of the latter group being aged 12 or more, compared to just three in the former. Again, younger children may be considered a more attractive proposition than older ones. Half those who remained on the waiting-list were non-ambulant, as were almost half the consumer sample, but again the distinguishing factor was age. Four of the non-ambulant waiting children were aged 12 or over, compared to only two of those in the consumer sample, the rest of whom were aged six or younger. Allen and Brown (1980), discussing the Northumberland scheme, found no link between 'severity of handicap' and ease in matching. They do, however, note that problems have arisen in placing non-ambulant children who require lifting. However, few differences were found between the groups in the present study in relation to other physical characteristics or in their level of self-help skills. Those who were not matched were less likely to be incontinent or epileptic. Fenwick (1986) compared 79 clients using the Face and Stop Respite Care Schemes in Newcastle with 30 clients waiting to use them. He tentatively concludes that those receiving the service were more severely handicapped than those waiting for it and suggests that older clients (in this case aged 16

eg girls
homeless

and over) were more difficult to match.

Unfortunately, data relating to the socio-occupational status of the 14 families on the waiting-list was incomplete, as was information about the children's behaviour. As social workers were not always able to supply the missing information, comparisons in these areas cannot be made.

Finally, it seems that the district in which families lived, in terms of departmental divisions, may be associated with successful placement, as Table 8.1 indicates.

TABLE 8.1 Comparison between Consumer Sample and 14 Families on Waiting-List in Terms of Departmental Division

Division	Consumers	Waiting Families
Edinburgh	8	4
West Lothian	5	2
Mid/East Lothian	2	8
Total	15	14

Again, it should be noted that of the eight children from Mid/East Lothian awaiting a match, six were aged 12 or over, and four were non-ambulant (three children showed all three characteristics). The scheme's slow development in East and Midlothian, up to and during the fieldwork period, has been attributed by its co-ordinator to a failure in securing commitment to its promotion at managerial level. In East Lothian, for example, difficulty arose in reaching agreement for local staff to become involved in carer recruitment campaigns. Cutbacks at local level, particularly, at that time, in resource workers for people with mental handicap exacerbated the problem. As a result, management of the scheme was held centrally, but the

geography and size of the division obstructed co-ordination of activity from Edinburgh. One social worker from East Lothian, who completed a postal questionnaire for the study, points to a high level of local interest, obstructed by lack of resources. She comments:

In this area, the scheme is barely operating. Despite recent publicity, no local carers came forward. We do not seem to have access to Edinburgh carers and there is no residential social work provision to fall back on for those on the waiting-list in the East side of the Region.

It should be added, however, that following the fieldwork period, a Share-the-Care worker has been appointed specifically to develop the scheme in Mid and East Lothian, deployed in a local social work department.

These findings correspond broadly to the agency's perceptions. As already noted, the co-ordinator of the scheme also identified problems in Mid and East Lothian. In a report to the Social Work Committee (Taylor, 1984) he stated that some children 'wait indefinitely because they present matching difficulties' and he refers in particular to lack of mobility, weight and hyperactivity. He later identifies older children who are wheelchair-bound as being hard to place.

Professionals who completed postal questionnaires for this study were asked what type of children, if any, they considered might be 'unsuitable' for the scheme. Nine replied that none need be perceived in this way, provided the right carers were available:

The child could be ugly, annoying, terminally ill, etc. etc. as long as the carers, their family and friends, can cope with them. The scheme should, wherever possible, be able to cope with the most needy and demanding families and children.

However, other social workers believed that the scheme might be unable to accommodate children with behavioural problems, or those who were frail, ill and in need of medical care.

Finally, the 30 carers interviewed for this study were asked what type of child they had in mind when they applied to the scheme. As Table 8.2 demonstrates, their responses strongly confirm the indication already noted that younger children are preferred, while heavier, immobile ones are less popular. Several were not prepared to take a hyperactive child, usually for fear of disrupting their own families. On the other hand, two carers specifically wanted a profoundly handicapped child with a high level of physical dependency.

TABLE 8.2 Carers' Initial Preference re Characteristics of Children

Preferred Characteristic	No. of Carers
Younger child (at least under 11)	18
Not heavy/immobile	9
Not hyperactive/disruptive	5
Prefer profound handicap	2
Other	5

In summary, examination of data relating to a group of 14 children who have been on the scheme's waiting-list for at least 18 months suggests, firstly, that older children (aged 12 or more) were particularly 'hard-to-place'; secondly, that families living in East and Midlothian were likely to remain on the waiting-list indefinitely, due to organisational difficulties within the scheme. Thirdly, lack of mobility did not appear to be a barrier to matching, except where it was combined with age, that is, older, non-ambulant children, who are likely to be large and heavy, tended to remain on

the waiting-list, but younger ones were successfully placed. These findings were confirmed by the perceptions of both agency and carers, who also identified hyperactivity as a problem.

The Study Sample (N=5)

I will now return to the five families from the original sample of 30 applicants who were still waiting for a match 7-10 months after their initial interviews. In order to explore the reasons why these families had not yet received a service, three main areas will be examined: the children's characteristics, the role of the agency and parental perceptions.

(a) Characteristics of the Children

In the light of the findings outlined above, it might be supposed that this sample, small as it is, would include some older, non-ambulant children, but this was not the case. Only one child was not mobile and required total bodily care and he was aged 4. None of the others had severe physical handicaps, compared to one in three of the whole sample and eight of the 15 in the consumer group. The four mobile children could feed themselves, although they needed some help with dressing, washing and toileting. Nor was age a significant factor, as they ranged from 4 to 10. Similarly their intellectual handicaps varied from mild to profound. There were three boys and two girls.

The difficulties involved in making 'objective assessments' of children's behaviour and the likelihood that different care-givers will perceive behaviour in differing ways has been noted elsewhere (Serbin, Steer and Lyons, 1983; Jeffree, Cheseldine and Shorron, 1981). Children (and adults) are likely to behave differently in response to varying environments and the nature of their interactions

with others (Martindale, 1982). It is not surprising, then, that differences in perception were found regarding the behaviour of these five children, all of whom in the view of social workers presented some problems in relation to matching. For example, one child was described by his mother as having no behavioural problems. She believed that his placid temperament should facilitate matching:

I am actually surprised he hasn't been fitted in quickly because he's not an aggressive child ... maybe if he was violent and aggressive and had you up all night ... I could understand it, but he's not. He's extremely placid.

The social work file, in contrast, refers to 'difficulty in matching due to a low level of response' and to the lack of 'a great deal of reward in working with him'.

Another mother believed that the social worker had an inaccurate and one-sided view of her daughter's behaviour, having only seen her at school. It should be stressed, however, that behavioural difficulties attributed to these children by social workers and also in two cases by their parents were comparable to those of about half the consumer sample, both in type and persistence. No conclusive findings can therefore be made about the behaviours themselves, nor whether the agency's perception of them may have contributed to delay in matching.

It might be speculated that parental attitudes towards sharing care could be a significant factor in determining speed of placement. It will be recalled that the agency had difficulty in matching one family from the consumer sample who had stipulated tight criteria for the type of carer they required. However, there was little evidence of this among 'parents who wait', most having clearly expressed 'inclusive' attitudes towards sharing care during the initial interviews. Similarly, the families were drawn from the three stress groupings.

In summary, contrary to what might be expected, neither the age nor the ability of these five children presented difficulties in relation to matching, nor were any other characteristics identified as significant. The agency's view of the children as presenting certain behavioural problems may have been a factor, but the behaviours themselves were comparable to those shown by children who were successfully matched. Finally, it should be noted that two of the five families lived in Mid/East Lothian; it has already been noted that children in this division were least likely to receive the service.

(b) The Role of the Agency

Three of these families applied to the scheme between November 1983 and May 1984 (as did two families from the consumer sample who waited longest for a match). A relatively successful carer recruitment campaign was held in Edinburgh in the Autumn of 1983, followed by preparation sessions in the New Year. These carers were matched to families who had applied during the same period, but, as is always the case within the scheme, demand outstripped supply. The scheme does not have a policy of allocating priority to the 'greatest need', but, rather, seeks to match parents and carers who appear most compatible on a number of fronts (see Chapter 1). In practice, however, the outcome for individual families may be partly determined by the style of their particular social worker, the pace at which s/he operates and the degree of pressure s/he is currently facing from his/her workload. In discussion, the co-ordinator of the scheme has suggested that if no suitable carers are available when parents apply, their application may be 'put on ice'; that is, it may be filed in a drawer marked 'waiting'. The danger is that these cases

may tend to receive less attention as time passes, perhaps particularly where a behavioural or access problem has been identified. Meanwhile, new applicants come forward and are matched to new carers. However, it is important to stress that some families who wait for over 10 months are eventually matched.

Another factor which contributed to delay in matching one particular family (who opted out of a second interview) is 'confused status'. That is to say, there appeared to be considerable confusion within the agency over whether this family still required/desired the service or whether, following a change in their circumstances, they were to be removed from the waiting-list. There were temporarily removed but later replaced. Partly due to this confusion, perhaps, little or no attempt was made to match them during the fieldwork period. Indeed, during this time, they were not visited by a social worker from the agency, although such a visit would have served a useful purpose in clarifying the situation. As I shall discuss in relation to families who withdrew, three others remained on the waiting-list and were perceived as 'active' cases long after the parents considered the application 'closed'. In short, the evidence suggests that a failure on the agency's part to make regular and systematic reviews of the waiting-list and to give some priority to families on it was an important factor in the delay experienced by these families.

(c) Parental Perceptions

As explained in Chapter 3, one family from this sample 'opted out' of a follow-up interview. Therefore, interviews were conducted with only four families. It will not be possible to draw any firm

conclusions from such a small number, but some common themes can be identified.

Without doubt, there was a lack of communication between the agency and the families and, as a result, parents lacked clear information about the progress of their applications. None apparently knew what stage it had reached:

No, I haven't been told anything. No idea.

No, we don't know anything about anything about it at all.
I was beginning to think they weren't bothering.

Three families reported that they had been given no explanation by the agency for the delay in placing them. In two cases, social workers had maintained regular, if infrequent contact (about once every three months), while the other two parents had apparently received no visits from their social worker since the initial research interview. One mother commented:

I think he could have contacted me just to say he hadn't forgotten me, after six months. A phone call or even a letter.

Among the 30 clients waiting for the Face and Stop schemes in Newcastle, more than half felt they had not been kept well-informed by the scheme. Fenwick (1986) concludes 'aspects of communications and/or case review require consideration if this situation is to be improved'. (p.28)

Another issue about which two families had strong feelings and which again is related to poor communication, was the fact that potential carers had visited their child at school, with a view to a possible match, but no further developments had materialised. It will be recalled that some criticism of this practice was made by the

consumer sample. Theoretically, parents are not supposed to know when such a visit has occurred, to protect their feelings should the carers decide against proceeding further. Both families, however, had heard about these visits - in one case, from three different sources! However, lack of information about why nothing further had transpired was a cause of considerable resentment, thus compounding parents' natural disappointment with this outcome. One couple, who waited a month to hear 'the result' of the school visit, did not accept the social worker's explanation that the carers were unable to proceed for personal reasons, but felt they were perceived as 'not good enough' (i.e. as socially 'inferior'). The mother commented:

[the social worker] never even said what the problem was, how the woman couldnae come, or anything. You have just got to take it what way you like. As I say, you don't know what to think or what not to think and we've had nae word fae Share-a-Care since ... If they are no wanting to give us anything, that's all right, we'll manage. We've managed up to the now.

Parents also lacked clear information about the channels of communication open to them. Should they have wished to inquire about their application, three were confused about whom to contact. Where a local social worker was also involved, there was some confusion over the respective roles and responsibilities of local and centrally-based workers. Two mothers had sent rather roundabout messages to the agency about their application through a third party. It was not clear if these had been received.

The fact that these families had not contacted the agency directly to inquire about their application was not linked to any lack of concern, nor to a decreased need for the service. Indeed, two families reported about the same level of need as when they first

applied, while the others reported an increased need and were appreciably more dissatisfied with the delay. It appears that poor feedback and lack of information from the agency led these families to wonder if the 'fault' lay with them or their child, thus discouraging them from initiating contact. One couple, as seen above, believed they were perceived as 'not good enough'; another mother was anxious that she might not be eligible for the service because she was a foreigner; a third jokingly implied that the reason for the delay lay in her son's unacceptable behaviour. Here the findings differ from Fenwick's: self-initiated contact by parents waiting for a service from the Face and Stop Schemes was not identified as a problem.

All four families had found an alternative source of occasional respite care. In one case this was an informal family-based arrangement. The other three were using or had applied to use institutional provision for short-term care, but reported they would not have done so had they received a service from Share-the-Care:

Using the hospital would never have come about if I had had Share-the-Care, because I was offered both about the same time and I turned down the hospital then and waited for Share-the-Care ... I hate [the hospital]. It's not, it's not the nurses' fault. It's a hospital, it's a hospital ... I just don't want him there.

Fenwick (1986) notes that clients awaiting a service from the Face and Stop Scheme were also 'obliged to a considerable extent to rely on hospital respite facilities'.

Summary and Conclusions

A group of 14 children who had waited at least 18 months for the service were compared with those in the 'consumer' sample. Indications emerged that older children, aged 12 or more, are particularly 'hard-to-place'; those who lack mobility face a double

if nothing else mentioned a 'hard-to-place'.

disadvantage; younger children are easier to match even if they are non-ambulant. These findings correspond to both agency perceptions and carers' preferences. Families living in Mid and East Lothian dominated the waiting group and this was linked to organisational difficulties within the scheme.

However, the five families in the study sample did not have older, non-ambulant children. Rather, although the numbers are very small, it seems that factors primarily relating to agency practice and procedures accounted for the delay in these cases. Because no suitable carers were identified when these families applied to the scheme, they were placed on the waiting-list. At this stage in the scheme's development, however, little systematic update or review of the waiting-list took place.

Two parents reported a lack of communication from the agency; three had been given no explanation for the delay and none were aware what action, if any, was currently being taken in relation to their application. In the absence of clear information and positive feedback, these parents had begun to wonder if they were perceived as in some way ineligible or unsuitable for the scheme. Their own failure to contact the agency was not therefore related to a decreased need for the service but, it was suggested, to a sense of having little control over the situation.

Finally, matters were further complicated where a local social worker was involved, due to some confusion over roles and responsibility between local and centrally-based workers. The implications of these findings for practice are discussed in the following chapter.

Part II - Families who Withdrew (N=9)

Introduction

Almost a third of the original sample of 30 applicants withdrew from the scheme, most before, but three after, having been linked to carers. None had used the service on more than four occasions. The other six families withdrew their application 3-7 months after submitting it. However, 'confused status', whereby the family considered the application closed (whether or not they had notified the social worker of their decision) while the agency continued to classify as active, meant that some remained on the waiting-list for longer.

This section begins by examining the characteristics of these children and families as a group, drawing on data from agency files and the initial interviews, in order to identify any variables which may have contributed to outcome. The reasons behind the decisions to withdraw will then be explored in detail. Finally, attention will be paid to families' use, and perceptions of, alternative forms of respite care.

Characteristics of Children and Families

There are 10 children in this sample, as it included the sibling pair. Data obtained from agency files showed that this group differed significantly from the whole sample of 30 and from the consumer sample of 15 in several respects.

Firstly, it is striking that eight of the ten children shared three characteristics: they were aged 8 or over; they were mobile and they were perceived by parents as presenting behavioural difficulties, in five cases, of a severe nature. Table 8.3 shows how these figures compare to the whole sample and to the consumer sample.

TABLE 8.3 Comparison of 'Withdrawn' Children and Other Samples

Variable	Whole Sample (N=31)		Consumer Sample (N=15)		Withdrawn Sample (N=10)	
	No	%	No	%	No	%
8-15 age group	20	64	9	60	8	80
Full mobility	17	54	5	33	8	80
Presence of behavioural difficulties (as seen by parents)	20	64	9	60	8	80

In most areas other than behaviour, the 'withdrawn' sample appears to compare favourably with consumer children. Their speech development was better; they were more likely to be continent, less likely to have any physical disability or to take medication. Similarly, they had more self-help skills. Half the children in the 'withdrawn' sample were not severely handicapped intellectually.

Families who withdrew were markedly larger than those in the consumer sample, over half the former having three or more children, compared to a quarter of the latter group. In contrast, a sample of 197 'non-users' of the Avon Family Support Service (only a small number of whom had 'withdrawn' from the scheme) tended to have fewer dependent children than did user families (Robinson, 1987). Children were also more likely than those in the consumer sample to live with both natural parents.

Six families fell into manual occupational groups, although this included three fathers who were currently unemployed.

During the initial interviews, this sample had identified a considerable number of stressors in their daily lives. Eight had reported some level of marital difficulty and in five cases, strong

indications had emerged of emotional disturbance among siblings. Several families also faced considerable external stressors in terms of long-term unemployment and financial hardship, four having been classified in Chapter 4 as suffering from socio-economic disadvantage.

It is interesting, then, to find that the sample consisted of one family from the low perceived stress group (psg), two from the high psg and six from the intermediate psg. It will be recalled that families in the intermediate psg were unlikely to identify the activity of caring as a major stressor but reported other sources of pressure in their daily lives. They tended to have large, two-parent families and had developed coping styles marked by self-sufficiency. Similarly, they were likely to express predominantly exclusive attitudes towards sharing care, which was true of seven families in the present sample. During the initial interviews, they articulated a dislike of 'stranger care', an ideology of personal responsibility for parenting, a preference for keeping the family unit together and/or anxiety about adverse separation reactions on the part of both child and parent. Indeed, three or four had been persuaded to join the scheme by professionals, largely against their own inclinations.

Analysis of information about this sample's informal support networks corresponds to findings outlined above. Most had regular contacts with a relatively high number of extended family members yet received little help from them in caring: only the sibling pair had experience of staying with relatives on a frequent basis and that was in the past. None of these families received assistance from friends, while only one had a neighbour who would childmind for several hours. Not only did these parents receive - or accept -

little help in caring for their child, it seems they tended to be socially isolated, seven reporting they had a night out together once in three months or less. Few maintained regular contacts with friends or neighbours. Kazak and Marvin (1984) argue that densely-knit, kin-dominated networks may create rather than reduce stress. Robinson (1987) reports that 'non-users' of the Avon Scheme were more likely than users to have effective informal support networks. On the other hand, mothers who choose not to use playgroup provision have been described as 'comparatively isolated in the community' (Shinman, 1981). They were less likely than playgroup users to have frequent contacts with their own mothers and other relatives and tended to dislike their neighbours.

A picture emerges, then, of older active children mostly free of physical disabilities, with relatively good self-help skills and, in half the cases, a mild or moderate mental handicap but with perceived behavioural problems. Their parents reported a number of stressors in their daily lives including socio-economic factors. However, caring was not usually defined as a major stressor with the exception of two high psg families. Most held 'exclusive' attitudes towards sharing care, apparently preferring to maintain the child within the family unit. It is not surprising then that during the initial interviews the majority had appeared ambivalent, if not resistant, to the prospect of joining Share-the-Care.

The Interviews

Although nine families withdrew from the scheme, one did not participate in a follow-up interview, the mother having left home and the child being placed with foster parents. Thus, eight interviews were held, between a fortnight and six months after the family

withdrew, as outlined in Chapter 3. In five cases, only the mother took part, in two, both parents participated, while one was conducted with a single father. Three were not tape-recorded at respondents' request. Additional data was obtained from interviews with two carers matched to these families and from agency records.

Reasons for Withdrawing

Table 8.4 summarises the reasons given by parents for their decision to withdraw, whether before or after matching took place.

TABLE 8.4 Reasons Reported by Parents for Withdrawing from the Scheme

Reason Cited	No. of Parents
Unsuitability of carers	6
Scheme created/would create pressures on family	5
Other source of help became available	4
Separation upset/would upset child	4
Prefer to keep family together	3
Child unlikely to be placed	2
Application dropped by agency	1

* Parents better

These factors are similar to the principal reasons cited by 197 'non-users' of the Avon Scheme; 52 reported no need for the service; 25 believed that responsibility for childcare should remain within the family while 15 believed that their child would not enjoy the experience (Robinson, 1987). Closer examination of the data indicates that the reasons for withdrawal were often complex and interdependent. Nevertheless, for the sake of clarity, they will be discussed separately as far as possible. Because the numbers are so small it will be necessary to go into some detail in individual cases.

(i) **Lack of perceived need**

Oswin (1984) has challenged an assumption sometimes made by professionals that parents will necessarily welcome a break from their child. She emphasises the normality of parents who

wish to keep their child at home because they love and enjoy him as much as their other children and who are worried about the separation and how it will affect their child.
(p.63)

Three families in the sample expressed little desire nor need to take an overnight break from their child. One mother who clearly derived enormous pleasure from her handicapped daughter, who was only 3, commented:

We wouldn't be a family without Joan with us.

Several parents expressed a strong preference to keep the family unit together as far as possible, believing that, in the child's absence, they would be missing a vital part of the whole. Another mother whose handicapped son was her only child explained how she and her husband had felt on the first occasion the boy had entered hospital for respite care:

We went out for a meal and just had a casual stroll along Princes Street and it was just ... nice, but Brian is part - I mean, its a unit. I don't honestly think that Share-the-Care would work for us.

As this comment indicates, a number of parents anticipated they would miss the child so much during periods of respite as to be unable to enjoy the 'break', a reaction which was experienced by one or two families in the consumer sample. Similarly, they were concerned that the child might be upset by the separation and would have difficulty in settling at the carers.

It might be questioned why these parents had joined the scheme in the first place if they were so dubious about using it. While

ambivalence will emerge as a central theme among families who withdrew, in three or four cases it seems that parents also came under some pressure to apply from professionals, a practice condemned by Oswin (1984). The inadvisability of persuading parents to join the scheme against their own inclination appears to be confirmed by the poor outcomes in these cases. A vital element in making the scheme acceptable to most families in the consumer sample was the scope it afforded for parental choice and control, but these facilitating factors are missing where parents feel constrained to join the scheme.

(ii) **Attitudes towards Shared Care**

Robinson (1986) notes of the Avon Service:

Quite a high percentage of families are unlikely to ever use the scheme whichever way it is organised since they would consider it is morally wrong to do so.
(p.43)

As noted already, seven families in this sample had expressed 'exclusive' attitudes towards sharing care during their initial interviews. Several believed that responsibility for looking after their own children should not be transferred to others, especially outwith the family. Thus one mother said of her husband:

[he] was against it from the start - he didn't like the idea of strangers looking after our children and he read about some volunteers in England, working with children, who were child molesters.

Hill (1984) relates similar fears among parents of non-handicapped children to cultural values about sharing care. 'Working class' families tend to worry about the risk of physical harm to their children, while 'middle class' families were more likely to be concerned about the child becoming emotionally distressed. In some

cases, anxieties about the carers' ability to cope were strengthened by aspects of the child's disability or perceived behavioural problems. One mother commented:

To try to introduce a hyperactive kiddy, that is very strong, when they are coming on for 8, to a scheme like that and to try to get a family to take them on ... quite frankly, I think Share-the-Care may be just not right for Bobby, I don't know.

Other factors in the child identified as likely to create difficulties for carers in looking after him, and thus for the agency in placing him, were illness, severe epilepsy and age, where the child was approaching the upper age limit for the scheme. These perceptions were confirmed for some parents by the experience of waiting several months for the service without success before deciding to withdraw, a point which will be developed later.

While some families feared that carers would have difficulty in coping with their child, one couple whose son had visited the carers four times before they decided to withdraw, clearly felt threatened not only by the carers' ability to manage the boy with relative ease, but also by their obvious enjoyment of doing so. His parents' consternation was increased by a dramatic improvement in the child's behaviour at the carers, compared to the considerable difficulties he presented them. For example, temper tantrums, apparently a common occurrence at home, ceased on arrival at the carers' doorstep, causing some resentment to the parents. His father commented:

They could ask to take trouble. We had to ask them to take trouble off our hands.

The carers reported that, while they found this child 'hard work', they greatly enjoyed his visits, the husband having formed a close relationship with the boy. Unfortunately, however, the child's

growing attachment to his new friends was also perceived as threatening. His father, who according to the carer 'absolutely adored the boy', commented:

It was hurting us, making us feel that he didn't want to be with us, because he was going on and on about wanting to be with the carers ... It was a helluva pressure. He would have wanted them to have adopted him next!

This reaction is in striking contrast to that of the consumer sample who, it will be recalled, were more likely to welcome the child's desire to return to the carers as a sign that she had settled well and enjoyed the visits. However, it is worth noting that anxiety about their children becoming 'too' attached to their childminders was found among Bryant, Harris and Newton's sample of mothers (1980).

(iii) **Socio-economic Disadvantage**

Among the families who withdrew were four who had earlier been identified as socially disadvantaged, a condition defined by Osborn, Butler and Morris (1984) as:

An accumulation of disadvantages and multiple problems which interact to impose concentrated stress on families.
(p.21)

Hill (1984) notes that while many aspects of shared care are not associated with class, including 'protectiveness', the nature of support networks and levels of parental self-confidence, both of which may affect patterns of shared care, are class related. One couple in the present sample felt some resentment towards their carers because the latter were seen as enjoying greater advantages than them in terms of employment, income, home ownership, community integration, and, finally, an active social life. The father openly admitted:

I was jealous. I've a chip on both shoulders. It was a barrier.

The perception of very real differences in lifestyle between themselves and the carers was a significant obstacle to the success of this match:

Our carers were a bit flighty. They wandered about in their dressing-gowns until 1 o'clock in the afternoon. We get up at 8 o'clock, get dressed, have our breakfast. They were a bit too casual. They had folk walking in and out of their house the whole time. Our backdoor is kept snibbed. I don't like people walking into my house.

The apparent disapproval expressed here is a measure of this family's discomfort with cultural behaviour and expectations different from their own. It has been argued that greater attention should be paid to families' core ideological values since these may form the basis of negative or positive reactions to service utilisation (Turnbull, Brotherson and Summers, 1984). In this case, it seems the couple sought to maintain a level of control by organising their lives around strict routines. Their carers' more easy-going lifestyle perhaps underlined the rigidity of their own and thus was perceived as threatening. Moreover, these routines which tended to revolve around the management of their hyperactive son, formed a coping device intended to reduce the associated stress, yet this couple discovered, on removing the child from the family, that stress persisted and was in fact exacerbated by his absence. It seems that when the child went to the carers, his parents suffered a loss of purpose. Childcare may be one of the few aspects of their lives over which families facing social disadvantage can still exercise some control. This may lead to an unwillingness to relinquish it, even for a short time. Indeed, this factor may distinguish between those highly stressed families who are able to benefit from the scheme and those who are not.

(iv) **The Role of Ambivalence**

Among mothers who make very irregular use of playgroup provision, tending to drop away, is one group said to be 'unusually ambivalent about their children'. Shinman (1981) describes them as feeling, on the one hand, deep concern and affection for their children, on the other, deep antagonism and resentment.

One couple who withdrew their application before being matched expressed concern that using the scheme might impair their ability to respond effectively to their son's frequent and severe epileptic attacks. His mother explained:

Brian had five attacks last night ... if we had been used to switching off, we wouldn't have woken up in time to turn him over so he wouldn't choke, so on balance maybe we are finding out the hard way, well the easy way really that maybe he's not the type of child for Share-the-Care.

These remarks illustrate graphically the considerable demands faced by some parents and the anxieties which respite care, or the prospect of it, might introduce by undermining well-established routines perceived as effective or even, in this case, as life-saving. Turnbull, Brotherson and Summers (1984) note that intervention services which interrupt family rhythm and create new demands may be experienced as stressful. Similarly, family systems theory suggests that family equilibrium, or 'homeostasis', can be upset by the removal of the member who acts as a regulator, a possible implication of using respite care (Walrond-Skynner, 1976).

It is striking that the mother quoted above chose the same phrase - 'switching off' - which was used by the family in the consumer sample who, it will be recalled, found that using the scheme had initially created many tensions, revealing how 'handicapped' they

normally were by their daughter's presence. This awareness had reawakened some disconcerting feelings about parenting a handicapped child, feelings which were usually lost in the daily demands of caring. The girl's parents had at first been fearful that, by allowing themselves to enjoy the child's absence on a short-term basis, they might come to wish for it in the long-term. It is possible that a significant factor in the decision to withdraw for some families is a fear of 'letting go' a little, for fear of 'letting go' altogether. To explore this complex issue further, it may be useful to look at another case in some detail.

One family who withdrew after being linked to the carers were described by their social worker as having 'major interaction problems', having developed somewhat unusual coping strategies. While the father had apparently 'rejected' his 3 year old daughter following a diagnosis of cerebral palsy, the 7 year old sibling was obsessively attached to the child, refusing to be parted from her and even sleeping at the foot of her bed to ensure that her breathing did not stop. (The child suffered from severe epilepsy.) Their mother seems to have adopted a highly ambivalent position. For example, she reported that she 'panicked' when the child had an epileptic seizure, leaving her elder daughter to call for an ambulance. Similarly, in an effort to encourage her non-ambulant daughter to walk, she placed her food at the far end of the room:

If she didn't crawl to it, she didn't get it.

This mother had clearly expressed her opposition to joining the scheme at initial interview, complaining that she had been pressurised into doing so by professionals. In the event her daughter had spent one day at the carers, without incident. The

elder child, however, was said to have sabotaged the arrangement by her outrageous behaviour during her sister's absence and by her continuing opposition to the match. Her mother commented:

[the social worker] came out to see us and asked if we wanted to give it another try and my husband said it was up to me because I'd have to cope with Megan (the sister) and I asked Megan and she said, no, she didn't like the carer.

Thus, the decision to withdraw was presented as coming from a 7 year old child, but it seems likely that to some extent she was articulating her mother's fears. This was certainly the carers' interpretation of events:

I think it was really coming from the mother. She kept saying, voicing everything in front of the older sister and she was saying 'Megan doesn't like [the handicapped child] going away from her because she doesn't think anybody's capable of looking after her'.

It seems that in this family two opposing impulses - to reject and to protect the handicapped child - existed side by side. This type of ambivalence, along with the 'boundary ambiguity' which marked roles and relationships within this family, can act as a major stressor (McCubbin and Patterson, 1983).

Furthermore, the child's absence forced her parents to confront other areas of difficulty within the family. How far these were originally associated with caring seems less important than the fact that they were now more keenly felt in the child's absence. Thus, this comment from the mother seems particularly significant:

[the handicapped child] does get a lot more attention paid to her ... Megan takes a backseat in here. As long as we are looking after her wee sister, Megan isn't bothered. We can forget about her.

When they were not looking after her wee sister, however, this couple could no longer forget about Megan but were made uncomfortably aware of her disturbed behaviour (which, in the social worker's view, required psychiatric help). Their reaction was to withdraw the handicapped child from the scheme and maintain her in the family unit. Walrond-Skynner (1976) notes that rigid family systems are unable to react creatively to change. Thus, when the identified 'family patient' is taken to hospital, she may improve but the family will collapse. This mother had earlier reported her own tendency towards depression and the existence of marital problems. It seems likely that in this family, and perhaps in some others, the activity of caring had come to dominate family life in order to provide some measure of displacement or distraction from other problems. It seems reasonable to conclude that families who have evolved this type of coping strategy are likely to be resistant to family-based respite care.

(v) The Boundaries of Family-based Respite Care

Strangely, perhaps, an experience shared by two families who withdrew from the scheme was that of having fallen out with their own parents, due to the latter's perceived rejection of the child. It can be no coincidence then that both reported they would have preferred to be matched to older carers, who could act as the child's 'grandparents'. Equally, they would hope to relate to such carers as their own parents, thus gaining direct personal support from themselves. One father commented:

We expected an older couple, a bit more mature, maybe like my own parents - more motherly, fatherly to me, to fill that gap, more stable and secure.

Clearly, these parents were looking for more support than the scheme was able to offer. In the event, however, the carers to whom this couple were linked felt disinclined to develop a relationship with the parents. The husband commented:

I would have liked to take the boy home, rather than his father coming here. I wished he wouldn't come and sit and I wasn't really interested in the parents. It was the kid I felt for.

This carer, who appears to be expressing some hostility towards the parents, did not attend any preparation sessions, believing that his own experience of parenting constituted sufficient 'training' for the role. Bryant, Harris and Newton (1980) found similar attitudes among childminders but conclude that personal experiences of parenting may not be sufficient preparation for developing positive relationships with other parents.

Another example of unrealistic or inappropriate expectations of the scheme is the case of a family which was in effect withdrawn from the waiting-list by the agency. Despite the fact that their son had become a weekly boarder at a new school, these parents still identified a need for family-based respite care. Their social worker, however, believed this would be unfair to their child, since the amount of time he would then be spending at home would be drastically reduced. Campbell (1983) points out that heavy or multiple use of short-term care can mask - or express - a need for longer term care.

Conversely, in another instance, a single father had been referred to Share-the-Care by a locally-based social worker in response to his request that his 14 year old daughter be taken into long-term care. Data from the initial interviews indicate that

coping strategies had all but broken down in this high psg family. The father carried virtually sole responsibility for caring for his daughter: this included bathing her and dealing with incontinence and menstruation, tasks he found increasingly difficult as she grew older. He was also responsible for bringing up two younger sons, one of whom was attending a psychologist. He was prevented from working by his daughter's dependency, resulting in long-term unemployment and financial hardship. This man traced the many stresses he faced to the care of his handicapped daughter:

A lot of the problem is living on social security. I can't work as long as I'm looking after Pam because she plays up when I'm not here. She's quite different with my girlfriend and with her two brothers, she goes for the younger one. And I have all the responsibility for looking after her. It's a lot of strain.

There is little sign here of the ambivalence identified in families from the intermediate psg. Rather, the child was clearly identified as the principle stressor and caring was seen as the source of other problems. Thus, removing her from the family was considered as the most effective means of eliminating stress. As a result, the scheme was quite unable to offer the level of support required. The girl was also receiving respite care for extensive periods in a local hospital. The social worker described the father as putting pressure on the carers to take his daughter 'more than is acceptable': when a fortnight's visit was arranged before the girl had been adequately prepared through shorter stays, she became very homesick and refused to stay. Subsequently she refused to return. She was received into long-term care a week or two later.

A final point to note in this case is the father's complaint that not only did his carer prove unreliable, failing to adhere to mutually agreed arrangements, but she also lacked sensitivity and understanding of his daughter's needs. Similarly, the social worker perceived the carer as having unrealistically high expectations of the child, as if unaware of the implications of mental handicap. Not surprisingly, perhaps, this carer had not attended any preparation sessions, nor did she make herself available for an interview for this study.

(vi) **Alternative Sources of Respite Care**

As Table 8.4 shows, four families reported that, among other reasons for withdrawing, a new sources of respite had become available to them. However, it emerged that two had been motivated to secure alternative sources of respite at least partly because several months had elapsed since they applied to Share-the-Care and they now perceived their prospects of placement as increasingly remote. One mother, who reported that she had received no communication from the agency for the six months prior to her withdrawal, commented:

I suppose I just assumed that, well, I mean people don't grow on trees, you know. It's difficult to find a carer I suppose and then it was only, as I say, as time went on, I thought, 'now this isn't going to work out too well in the end' you know.

Her comments are reminiscent of parents in the 'waiting' sample, indicating poor communication and inadequate feedback from the agency.

The 'new sources of help' referred to by other parents were, in one case, the offer of help from a relative which had been accepted

in principle but not yet used in practice and, secondly, a reciprocal childminding arrangement with a neighbour. However, as these families also expressed considerable ambivalence about using family-based respite care, the availability of a new source of help was not a major factor although it may have been seen as the most acceptable one to present to the agency.

Table 8.5 illustrates the types of respite care used by families between the two study interviews.

TABLE 8.5 Sources of Respite Care used between Study Interviews by Parents who Withdrew

Source of Respite	No. of Families
Institutional	4
Day carers	2
None	2
Weekly Boarding School	1
Total	9

Institutional Care

Substantial indications emerged that several families who withdrew from Share-the-Care preferred to use institutional care. Indeed, five were currently doing so at the time of the follow-up interviews (including a weekly boarding school), while a further two indicated a readiness to do so should the need arise. No child in the sample had stayed overnight with friends, relatives or neighbours. It was suggested earlier that some parents felt threatened by the prospect of another 'ordinary' family coping quite happily with their child. This may be particularly true where the real need was for long-term care, as, in one case, it was.

'Professional' care, on the other hand, may be less threatening, because staff are seen as having been specially recruited and trained for the job, often with extensive experience. These factors may be perceived by parents as representing some acknowledgement of the heavy demands which they face on a daily basis, thus exonerating their decision to seek respite. One family, for example, continued to use a hospital for respite every second weekend throughout the few weeks of their match and afterwards. Their social worker commented:

[their] confidence took a knock when they discovered others could care for their child. They felt threatened by the carers and reverted to anonymous/comfortable hospital relief care.

In the institutional setting, a number of different staff are involved in looking after the child, thus reducing his opportunity to form close, one-to-one attachments, an element of family-based care which some parents found threatening. Similarly, parents themselves are not required to make the same sort of input to organising institutional care which is demanded by Share-the-Care. In particular, they are not asked to form a personal relationship with residential workers nor medical staff, while negotiating respite with a hospital is unlikely to carry the overtones of 'asking for a favour' which some parents encountered in relation to carers. The difference is reinforced by the fact that professional staff are paid: parents need not feel indebted to them, nor that they owe them something in return. Finally, where parents have been accustomed to using institutional respite on a regular basis, the very flexibility of Share-the-Care may be experienced as stressful, because it involves deviating from well-established routines, which were an integral part of families' coping strategies, and is less

'predictable'; for example, carers might be unable to have the child on a regular, fixed basis. In summary, it seems that, whereas the consumer group tended to prefer family-based respite because their confidence in the situation allowed them to relax and benefit from the break, which most found difficult when the child was in an institutional setting, about half the withdrawn sample showed the opposite reaction. They felt unable to relax using family-based respite but were more comfortable with institutional provision.

Day Care

On the other hand, two families had started to use day-care provision; in one case, through a Befriending Scheme run by a voluntary organisation; in the other, a statutory Day-Care Service. Both were well-satisfied with this provision, principally because, while they felt the need for regular short breaks from caring, they were unwilling to let the child stay away overnight. One mother commented:

It's alright when you're away during the day;
during the night is a different thing altogether.
And we kept on ... we keep ... We waken up listening
for him. We sort of say, 'where is he?'

One or two parents seemed to be under the impression that Share-the-Care necessarily involved overnight or even prolonged stays away from home, which greatly increased their reluctance to use it. It is possible that had there been more emphasis on the availability of day-care through the scheme, they and others like them might have been readier to use it. Robinson (1986), discussing the needs of non-users of the Avon Scheme, calls for more home-based services, including sitters and home care assistance.

Summary and Conclusions

The ten children in this sample were, on the whole, relatively able, having few physical disabilities and comparatively good self-care skills. The majority had a mild or moderate intellectual handicap. Almost all, however, were perceived by their parents as presenting behavioural problems, often of a severe nature.

Seven parents in this sample had earlier been identified as holding 'exclusive' attitudes towards sharing care, four having been persuaded to join the scheme by professionals against their own inclination. Two-thirds were from the intermediate psg, likely to identify certain areas of difficulty in their lives, but less likely to relate these to caring.

Campbell (1983) and Oswin (1984) have challenged a tendency in professionals to treat respite care as a panacea for all ills, based on the perception that separating child from family will reduce stress and thus, presumably, help resolve any other areas of difficulty. It is clear from the findings of this chapter that such is not necessarily the case. Important distinctions should be made between different types of family situation. Some parents clearly enjoy looking after their child and feel neither wish nor need to take a break from caring. Others, who do feel under some stress, are nevertheless resistant to using family-based respite but may be amenable to other forms of support. The scheme is not a viable option where the real need is for long-term care. In all these cases, to a greater or lesser degree, the experience - or prospect - of using the service, far from alleviating stress, appeared to create or exacerbate it. This reaction may be increased by the presence of particularly ambivalent feelings about the child and her future care

or where family interaction was seriously disturbed, both factors being highlighted by the child's absence. Although numbers are very small, indications emerged that families who face socio-economic disadvantage will experience difficulty in using the scheme and are likely to withdraw. This variable may distinguish between those highly stressed families who are able to benefit from family-based respite and those who are not.

As only three carers had been linked to families in this sample, no conclusions can be drawn about contributions they may have made towards the breakdowns. However, traces of hostility towards parents or child were identified in two who had not attended any preparation sessions.

Social workers also made some contributions to outcomes, by referring families inappropriately and apparently without adequate discussion and preparation. It was also noted that two families had withdrawn their applications at least partly because, having been on the waiting-list for several months, they did not think they were going to be successfully placed and thus secured alternative provision.

Indeed, various aspects of institutional respite care were identified which made these options more acceptable to several parents, while two preferred to use day-care. It was speculated that some families might have been prepared to consider alternative resources, such as domiciliary support, had these been more readily available.

Finally, in common with the findings made throughout the study, it is clear that parents vary greatly in their expectations, perceptions and experiences of using family-based respite care. It

must be concluded that the scheme is not an appropriate resource for all families nor situations and that a wider package of services is required, offering parents some degree of choice and flexibility. The implications of these findings for practice are discussed in the following chapter.

PART III

CHAPTER 9

Conclusions and Implications for Policy, Practice and Future Research

Introduction

It is now widely accepted that institutional care is not generally appropriate for children, including those with disabilities, either in the long or the short-term; indeed, the vast majority of handicapped children in Britain live at home with their families. At the same time, however, research over recent years has shown, firstly, that the presence of a handicapped child can act as a stressor within the family and, secondly, that parents may benefit from regular breaks from the caring role. Respite care, which has been provided in a variety of hospital settings since the early 1950s, is now available through residential units, hostels and special school annexes. Family-based schemes, which started in Britain in 1976, aim to reflect principles of normalisation, community care and good childcare practice. The service is intended to be informal, flexible and easily accessible to parents.

Over the past five years, family-based respite care has expanded rapidly, particularly in England and Wales, but its development has been patchy and unstructured, isolated from any coherent social policy or national guidelines. In the absence of much detailed evaluation, the service appears to have met with largely uncritical acceptance. The present study, then, aims not only to evaluate the effectiveness of the Lothian Scheme and its impact on the lives of its users, but also to go some way towards filling the gaps in existing knowledge about family-based respite care.

This concluding chapter begins with a summary of the main findings and then examines their implications for policy, practice and future research.

Summary of the Main Findings

It may be useful to begin by making explicit a major conclusion of the research: the scheme has proved successful in meeting the needs and expectations of a substantial proportion of families who identified a range of benefits from using the scheme. Parents' confidence in the quality of childcare provided by carers was a vital factor in their ability to relax during the breaks. This reaction was sometimes contrasted with their feelings of anxiety when the child was in hospital, for medical or 'social' reasons. Indeed, the benefit most often identified by parents was a regular opportunity to relax, corresponding to findings about other schemes (Bird, 1982; Fenwick, 1986). Additional benefits identified by the parents included the freedom to pursue their own interests, having time to spend with each other and the rest of the family, improved marital relationships and a sense of security in relation to childcare provision, particularly in case of emergency.

Most parents also pointed to a range of benefits to the handicapped child, particularly her close attachment to the carer and obvious enjoyment of the visits. In some cases, parents reported gains in the child's social skills or capacity for independence. It should be stressed that the majority of children in the consumer sample had severe and sometimes profound/multiple handicaps. Contrary to what might be expected, those who were successfully placed were found to have more severe disabilities and fewer self-help skills than those who were not. As a group, however, they

tended to be relatively young - most aged 10 and under. Information obtained from agency records indicate that older children are likely to remain on the waiting-list indefinitely, particularly if they are non-ambulant. This finding corresponds to many carers' stated preferences for younger children, while older, heavier and hyperactive ones were generally viewed less enthusiastically.

However, these characteristics did not apply to the five 'study children' who had not received the service 6-9 months after applying for it. Rather, it seems that factors relating to agency practice and procedures mainly accounted for the delay in these cases. Evidence emerged that the agency failed to maintain good contact with some of these families, to make regular reviews of the waiting-list and to update relevant information. Some confusion of roles and responsibilities existed between central and locally-based social workers, sometimes resulting in misunderstandings about continuing need for the service.

Although it was not an objective of this study to determine which factors might be associated with the incidence of stress among families, yet some findings were made in this area. No link was found between the severity of handicap and degree of perceived stress, corresponding to the findings of Bradshaw and Lawton (1978) and Kendall (1982). The incidence of high perceived stress tended to coincide however with double incontinence in the child and a perceived need for virtually constant supervision, usually due to behavioural difficulties, corresponding to the findings of Glendinning (1983). It was also noted that children whose parents were highly stressed were often from a younger age group - seven or under. Although the numbers were small, it seems that while socio-

mobility
11/87

occupational status was not in itself related to stress, social disadvantage, not surprisingly, did act as an additional and significant stressor. It was also found that low level stress was associated with a wider and more active informal support network and with a high frequency of short periods of respite.

It was noted in Chapter 2 that Cunningham and Byrne (1985) have called for an exploration of parents' coping strategies and the resources needed to sustain them. Although it was outwith the remit of the present study to make a detailed examination of their broader coping strategies, nevertheless it did emerge that parents differed not only in their levels of perceived stress but also in their coping styles. Among the different resources employed, the role of subjective perceptions and the definitions given to their situation appeared crucial, with significant differences of meaning being attached to caring by different families. These findings are similar to those of Folkman, Schaefer and Lazarus (1979) and Venters (1981). Again, this indicates, as Mink, Nihira and Meyers (1983) have pointed out, that families with handicapped children are not an homogeneous group, as they have sometimes been conceptualised in the past. Indeed, the range of attitudes displayed by parents in the present study towards sharing care corresponded closely to that shown by parents of non-handicapped children, albeit of a younger average age (Backett, 1982; Hill, 1984).

The findings indicate that families also vary greatly in their experiences of using family-based respite care. Those most likely to be placed on the scheme and least likely to withdraw at an early stage were those who had originally presented themselves as under least stress and had not expressed an urgent need for respite.

Although not without some initial reservations, most adjusted to using the service with relative ease. These were parents who defined most aspects of family life, including caring, in positive terms, tending to liken themselves to parents of non-handicapped children. Most were accustomed to making effective use of external supports and to having regular short breaks from their child, in line with their predominantly inclusive attitudes towards sharing care.

However, the scheme is also well able to accommodate a substantial proportion of those who experience high stress and require more immediate relief. These families tended to view caring as the principal stressor in their lives and the source of other difficulties. Thus, removing the child for short periods was experienced as beneficial and brought improvements in other areas of family life. On the other hand, they experienced greater difficulty than others in using the service at first, particularly in asking their carers to take the child and thus required more active social work support. This finding can be related to Bulbolz and Whiren's argument (1984) that those with least energy may experience greatest difficulty in securing and utilising external supports. However, the scheme could not provide sufficient support where coping strategies had all but broken down and the real need was for long-term care. Although numbers are small, the study suggests that highly stressed families who are also socially disadvantaged may be likely to withdraw. It was speculated that the introduction of other practical or material supports may be required before they can benefit from the scheme.

Almost a third of the original sample of 30 applicants withdrew from the scheme during the fieldwork period, either before or after

being linked to carers. Some felt little or no need for respite care, but had been 'persuaded' to join the scheme by professionals. Others, who did feel under some stress, were resistant to using the service because it involved separation from their child and/or 'stranger care'. Coping strategies marked by a high degree of self-sufficiency, based on an ideology of personal responsibility for parenting, and sometimes associated with social isolation, were likely to come into conflict with the demands of family-based respite care. Where care routines are long established, perhaps dominating the household, and dependency and attachments particularly strong, removal of the child may upset family equilibrium, creating or exacerbating stress. Thus, while family-based respite care can clearly be conceptualised as an effective social support for some families, for others it may act as an additional stressor, bearing out Waisbren's thesis (1980) that such supports do not necessarily act as a buffer between the family and stress.

Turning now to the carers, the majority were married couples with an average age of 39-40. The sample was almost equally divided between those with manual and non-manual occupational backgrounds. Over half the female carers were working, while only one man was unemployed. Two-thirds were owner-occupiers. In several respects, then, they differ significantly from traditional foster parents. On average they had two children per family, most of whom were aged over five.

A strikingly high proportion (22 out of 30) had extensive previous contacts with people with mental handicap before joining the scheme. Several, for example, had a handicapped relative, while over half were employed in 'the caring professions'. Experience of

voluntary work and of fostering or adoption was also common. These findings correspond to three main areas of motivation identified among carers for joining the scheme: a commitment to people with mental handicap, a fondness for children and a desire to be of service to others, indicating that carers are drawn from specific sections of the community and have a 'predisposition' for the role. However, it is important to stress that the desire to meet needs of their own was also a strong - and legitimate - factor in their decision. Similarly, several had clear ideas about the level of commitment they were prepared to make to the scheme, and the type of child for whom they were willing to care.

Most carers clearly derived great satisfaction from their activities, such as their fondness for the individual child, the benefits accruing to their own children and the reward of doing something worthwhile in their spare time. Nearly half had difficulty identifying any drawbacks. Most presented caring as undistruptive to normal family life, while any practical difficulties which had occurred were generally described as minor. Although it is hard to judge whether carers tended to underestimate any problems they experienced, a strong sense emerged of the 'everydayness' of caring, corresponding to Robinson's findings about the Avon Scheme (1987).

The majority of carers perceived their role as a 'caring hobby' rather than a professional task. They conceived of it in terms of their personal commitment to a particular child or as acting in a neighbourly way towards her parents. A few would have preferred to receive no fee, while many saw the purpose of payment only as the reimbursement of expenses, corresponding to the perceptions of traditional foster parents (Fanshel, 1966; Triseliotis, 1980).

However, these carers were relatively well-off and unlikely to be deterred from caring, as others might be, through anxiety about incurring extra expenditure. Again, several believed the payment served a vital function in formalising the process of sharing care.

Some carers appeared to have drawn firm boundaries around their commitment to the scheme, which they were unwilling to extend. This was particularly true of those who had been predominantly motivated by the desire to be of service to others, who appeared to have made less emotional investment than others in their role and to derive less satisfaction from it. Those with a positive commitment to people with mental handicap were more likely to perceive scope for a 'professional' orientation to their activities. Finally, some carers who were particularly attached to the child and willing to extend their commitment to the scheme within its present structure were strongly opposed to the concept of professionalisation, perceiving this development as contrary to the scheme's ethos.

Certainly, evidence did emerge that the present, semi-voluntary status of carers is an important factor in facilitating the process of sharing care for some parents, by enhancing their sense of security and trust in the situation. For other parents, however, it is a deterrent, since it limits their ability to exercise choice and control. A remarkable finding of this study, which runs counter to the original 'philosophy' of the scheme, is the extent to which many parents experienced difficulty in negotiating respite. In only a minority of cases did they regularly initiate arrangements, by asking the carers to have the child. Some would only do so if they had a special, (that is, a 'legitimate') reason, such as a family wedding. Parents cited a number of factors in explanation of their widespread

reluctance to ask for a break, often related to their perception of carers as altruistic volunteers. Many were worried, for example, about 'imposing' on carers or draining supplies of goodwill through 'excessive' requests for respite. Others felt concerned about the non-reciprocal nature of the arrangements and wondered how they could ever repay the carers. Additional worries included a fear of seeming to 'reject' the child or appearing unable to cope without external support. To some parents, the idea of sharing care outwith the immediate family was quite alien. One or two felt bereft without their child, seeming to suffer a loss of purpose in her absence. Conversely, the experience of respite could reawaken disconcerting feelings about parenting a handicapped child, by giving the rest of the family an unfamiliar taste of 'normal family life'. In order to sustain matches where parents experienced difficulty in asking for a break, about a third of the carers regularly invited the child to stay. Unwittingly, however, this could create the danger of parents feeling obliged to fit in to whatever package of breaks was proposed by carers, whether or not it corresponded to their needs, or the child's.

The matches which operated most successfully were often those in which responsibility for making arrangements was shared between both parties. In these cases, carers and parents tended to describe their relationships as 'friendly but not friends', several commenting that a 'businesslike' arrangement worked best. Parents often thought the development of too close a friendship between themselves and the carers would only increase their fears of imposing. Throughout both samples, an emphasis was placed on the carers being the child's special friends rather than the parents'.

These findings are important, since they belie any assumption that parents usually take the initiative in arranging periods of respite or that, once introductions have been carried out, social workers can withdraw to the background, leaving the matches 'to run themselves'. Furthermore, contrary again to what might be expected, use of family-based respite care is not necessarily a straightforward matter, but can raise complex and disturbing issues for parents. Reactions vary greatly between different families, often related to their levels of perceived stress, their perceptions of caring, attitudes towards shared care and existing coping styles.

Like several recent studies of foster care (Berridge and Cleaver, 1986) the study shows a need to develop and strengthen the preparation and support of carers, parents and children alike. Severe homesickness and distress emerged as a significant factor in about a third of the children, linked to a combination of factors, such as the timing, length and frequency of visits, the nature of children's previous separation experiences and the parent/child attachment. Indeed, the agency had failed to identify homesickness as an issue of potential relevance to all matches and, as a result, no strategies had been developed for reducing or responding to it.

Implication for Policy

(a) The Values, Principles and Philosophy of Family-based Respite Care

Many of the findings summarised above provide a strong argument for the expansion and development of Share-the-Care in order to benefit a greater number of families. At the same time, the study has identified certain areas of difficulty within the present structure of the service, bringing into the question the basis on

which future development should take place. If it is to be assumed that the scheme's structure should reflect its basic principles and value-base, it may be useful to begin by clarifying these.

Family-based respite care has been conceptualised both as a variant of fostering (Shaw and Hipgrave, 1983; Oswin, 1984) and as an example of 'informal caring' (Campbell, 1983). Although its origins may owe something to each tradition, and while it contains elements which resemble each, yet its function and objectives remain distinctive.

The difficulty of finding an adequate definition of 'fostering', particularly since that term is now used to cover a variety of different activities, has been noted elsewhere (Triseliotis, 1986). However, for the present purpose, it may be conceptualised as the provision of substitute or supplementary care, on an emergency, short or long-term basis, to children whose parents are unable, for a variety of reasons, to look after them. Although the circumstances leading to foster care placement vary greatly, still its very nature requires that it operate within a tightly controlled and closely supervised structure. Thus, it carries a statutory component, involves certain legal safeguards and requirements, maintains strict monitoring controls and may require intensive social work input.

In contrast, family-based respite care aims to provide regular complementary care as a form of ongoing support to parents raising a child with disabilities. It represents an acknowledgement that this can be a demanding and exhausting activity, along with an assumption that parents will benefit from a break which involves separation from their child (although this and other research has shown that such is not always the case). It may be used when parents are under

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particular stress, but is also designed for the times when they are coping effectively. Thus, it should not be perceived simply as emergency, occasional nor holiday relief. The lack of statutory admission into care was a vital element in making the scheme attractive and acceptable to many parents in this study, along with the absence of cumbersome bureaucratic procedures. Many welcomed the informality of the assessment process and the introductory meetings. As several pointed out, they are also free to make choices and decisions about the timing, length and frequency of visits.

In order to avoid creating stigma or 'labelling' parents, it seems right that family-based respite care should offer a universal, as opposed to a selective, service, involving neither tests of eligibility nor systems of priority allocation. Use of the service should be entirely voluntary. Some parents may need encouragement to join but should not be pressurised against their will. Parents and carers are encouraged to develop informal friendly relationships and to make their own arrangements for care. The role of the social worker is facilitating rather than supervisory. Finally, the service is based on the conviction that children with disabilities have a right to enjoy the same types of experience, lifestyle and environment as any others.

It is less easy to define the nature of 'informal caring' precisely because, unlike fostering, the activity has a low profile, goes largely undocumented and is carried out on a private and individual basis. The Barclay Report (1982) refers to 'informal caring networks', to signify lay persons who elect to provide varying forms and levels of support to their relatives, friends or neighbours, motivated by the ties of family or friendship, or a sense

of community spirit. However, the very nature of informal caring means that it lacks any comprehensive, organised structure (despite some recent attempts to develop one, as in the establishment of the National Association of Carers). Because it is carried out by thousands of individuals acting in isolation and in a voluntary capacity, it has no reference to concepts such as accountability nor monitoring, no inbuilt safeguards to ensure either continuity or quality of care, nor any supportive backup system which can intervene if difficulties arise. Therefore, although informal caring may have certain superficial similarities to family-based respite care, it would not appear to provide an appropriate model for the latter's development.

Yet Campbell (1983), warning against the dangers of 'denormalising' the service, appears to imply otherwise. She has suggested that the provision of support systems to carers, such as the loan of equipment, the payment of expenses and any form of sustained social work contact may have that effect. Her point seems to argue for a perception of respite carers as 'the family next door' choosing to act in a neighbourly way, as if in isolation from the organisation running the service. Given this philosophy, social workers would need to adopt a 'laissez-faire' approach, leaving both parties to their own devices. Some schemes have attempted this type of unstructured operation - without success (Goodenough, 1984; Caudrey, 1984) and the results of this study would not support it.

Furthermore, research has shown that the majority of 'informal caring' takes place within the family home and is performed by women (Finch and Groves, 1983). Neighbours make a very small contribution to informal caring and less is provided by friends. These findings

were also made among the present sample, most of whom were loathe to seek regular assistance with childcare from their friends or neighbours, particularly if they felt unable to reciprocate.

Research has repeatedly shown that, in order to be useful and acceptable, support must be offered to parents in a way which involves them as partners and which can be readily accommodated within their existing coping strategies. This and other studies have suggested that families differ in their coping styles and therefore what works for one will not necessarily work for another. It is likely, then, that no one structure of shared care will suit all parents.

In conclusion, family-based respite family care might be conceptualised as informal caring within the context of service provision, based on five main principles: good childcare practice, normalisation, universality, parental choice and control and, lastly, continuity and reliability of support. Given this broad philosophy, it should be clear that neither the formal, bureaucratic and complex structure of fostering, nor the amorphous 'laissez-faire' approach associated with informal caring, would be appropriate. Rather, the service should aim to achieve a balance between the two, allowing for flexibility, informality and ease of access on the one hand, while on the other, consistency, adequate safeguards and, above all, clarity in the roles, relationships and responsibilities of parents, carers and social workers.

(b) The Role of Carers : Caring Hobby or Professional Task?

It may be argued that the principles outlined above are compromised, at least to some extent, by the present structure of Share-the-Care or, to be more precise, by the semi-voluntary status

of carers. Parental ability to exercise choice and control, for example, may be drastically reduced where parents are obstructed from asking for a break through anxieties about imposing on carers, draining their goodwill or about the non-reciprocal nature of arrangements. Clarity in roles and relationships will be missing as long as it remains uncertain whether parents are receiving a service or a favour from the carers, where the latter may perceive their social worker as a friend or as a colleague and so on. Flexibility and ease of access may be threatened when carers can draw boundaries of their own making around their commitment to the scheme yet, due to their voluntary standing, the agency is greatly restricted in the requirements it can make of them. It might even be suggested that the scheme cannot offer a universal service so long as carers can choose not to take older non-ambulant children or those who are hyperactive. Finally, it was found that carers were more likely to identify difficulties within matches than were parents, who were reluctant to raise certain problems with their social workers. Oswin (1984) who made a similar finding in relation to residential short-term care, suggests that parents were discouraged from expressing any concerns or complaints at least partly because they feared they might lose the service as a result.

One way to overcome these not inconsiderable difficulties might be the introduction of 'professional' carers, working to a fuller contract and receiving payment equivalent to a salary. Such carers could be matched to a maximum of three or four children each. Parents who feel impeded by voluntary carers might be more inclined to seek support from carers whose job it is to provide them with that service and who are receiving tangible, if material, rewards. Two or

three parents commented that carers should receive higher rates of remuneration. The agency might give some attention to the experience of the Avon Service, the largest scheme in Britain, which employs carers as full or part-time workers. The difficulties in negotiating respite experienced in Lothian have not arisen there, while remarkably few families express the same ambivalence about using the scheme (Robinson, 1986).

Professional carers could be required to work to a fuller contract than do 'voluntary' ones. They could be expected, for example, to attend full preparation sessions, group meetings and, from time to time, training workshops. This would help to secure a consistently high standard of care, along with a sensitive understanding of parents' needs, on the part of all carers.

Similarly, it is possible that this system might attract parents who are reluctant to use the scheme because they perceive carers as 'lay people', lacking special skills and knowledge, and therefore unqualified for the task. Such anxieties might be overcome if carers were to gain a more 'professional' image.

The introduction of such carers could be used to afford parents greater choice in matching procedures. Several expressed a strong dislike of the present system, on the grounds that it appears to allow greater choice to carers. Social workers would still have an important role in identifying carers who have a 'vacancy' and who would be broadly compatible with a natural family. Wherever possible, however, the latter could then be shown two or three 'carer profiles' from which to choose whom they would like to meet.

Similarly, it was found that non-ambulant children aged 11 or older were liable to remain on the waiting-list indefinitely,

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corresponding to carers' stated preferences. Hyperactive children were also perceived by the agency as 'hard to place'. In order to provide a service to these children and their families, carers with special skills and aptitudes may be required, whose needs for training, support and remuneration may differ from those of voluntary carers.

Thus far, I have examined the arguments in favour of introducing professional carers. On the other hand, however, a strong case against doing so can also be developed from the results of the study. A number of parents had expressed scepticism, if not outright suspicion, about carers' motivations for joining the scheme and were clearly reassured by the fact that the latter did not receive substantial payment. The introduction of a salary would doubtless fuel anxieties that carers were only financially motivated and might well deter some parents from using the scheme altogether. However, the agency could publicise the fact that professional carers undergo tight screening and stringent assessment, while also receiving fuller preparation and more intensive training than do voluntary carers.

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Parents' anxieties about carers' motivations can be linked into a wider debate about the desirability and, indeed, the morality of receiving financial remuneration for childcare. While the receipt of state benefits for the support of one's own children is now widely accepted, attitudes towards payment as a reward for looking after other people's children remain mixed. Following scandals about 'baby-farming' towards the end of the last century, it was considered advisable to pay foster parents little more than the cost of providing for children (Packman, 1981). However, with the emergence of treatment and specialist fostering in the 1970s, it was recognised

that more was required than the possession of ordinary parenting skills, hitherto considered the main qualification (Shaw and Hipgrave, 1983). The payment of a professional fee recognises and rewards the extra skills and knowledge involved, while also enabling practitioners to make certain demands of foster parents. More recently, allowances have been introduced for certain types of adoption, a development generally welcomed by both adopters and professionals (Triseliotis and Hill, 1986). However, particular objections may be made to paying respite carers of handicapped children. While their care is likely to be more expensive than that of others, yet their own parents receive only limited financial assistance for supporting them in the long-term. They may well feel understandable resentment if those who look after their children in the short-term receive a higher rate of support.

On the other hand, it may be worth noting that two-thirds of the Avon sample ($n = 104$) thought their carers' payment 'about right', while nearly a quarter believed it was too low. Only 11% considered it too high. Among a sample of 197 non-users, no evidence emerged that parents were deterred from using the service because carers were paid for their efforts.

However, leaving aside objections to the basic principle of payment for childcare, it may be argued that the introduction of professional carers would result in a reduced quality of childcare. Parents tend to place great importance on their perception of the carers' commitment to the child as based on genuine personal attachment rather than contractual agreement and may therefore sense a qualitative difference in the nature of that relationship. Again,

some gain a sense of long-term security from the 'personal' nature of the attachment because it seems to suggest the match will continue indefinitely. This attitude was not problematic where carers took a similar view, but some did not. Another feature of the current service valued by parents is the one-to-one relationship it entails. There may be anxieties that carers matched to three or four children would be unable to provide the same amount of individual attention. Serious problems have arisen in Avon because carers are linked to excessive numbers of children (up to 15 in the worst case), thus creating 'mini-institutions' within a supposedly normal family environment. In order to safeguard the principle of normalisation and good childcare practice, Robinson (1986) recommends a maximum of four children per carer. Again, care should be taken to ensure that only one child visited the carer at any time. On the other hand, such arrangements might well reduce parents' scope for flexibility and choice in negotiating respite.

A final argument which can be raised against the introduction of professional carers is that such a development runs counter to the ethos of many present carers. Several expressed ambivalent feelings about receiving any payment whatsoever for their activities. The majority did not wish to 'care' as a part-time job and some were strongly opposed to the idea of professionalisation, as were traditional foster parents to the introduction of specialist fostering. On the other hand, about a third of the sample did express some interest in the possibility of part-time work as carers, particularly those who had entered the scheme with a positive commitment to people with mental handicap. The findings from the Avon Report regarding the personal and social characteristics of

carers suggest that the type of person involved in professional caring is remarkably similar to the voluntary carer in Lothian. Both had similar backgrounds in fostering and adoption and in extensive previous contacts with people with handicap. They also had similar motivations for joining the scheme. It may be significant that, among the present sample, (n = 30) 17 were currently employed in the 'caring professions', including specialist fostering or adoption, five had been so in the past, while only seven had not. They perceived their involvement in the scheme as a caring hobby partly because it was secondary to their existing occupational commitments. Therefore, it seems likely that a similar type of person but one who is actively seeking work might be attracted to becoming a professional carer.

Thus far, it has been suggested that while the introduction of professional carers would facilitate the process of sharing care for some families, it might impede others, yet the voluntary status of carers appears to have a similar effect. Although the majority of existing carers were not interested in part-time work, the study has shown that they provided a high standard of care, greatly valued by parents, while also deriving considerable satisfaction from the activity themselves. Many were clearly very attached to the children, as were the latter to them. The scheme cannot afford to lose these carers, nor the many potential future volunteers for the caring hobby. A third option then would be to operate a two-tier system of care. Such a system, involving both 'professional' and 'voluntary' carers, would operate within a single co-ordinated service. Indeed, it would seem very likely that, if professional carers are to be introduced, the scheme will have to operate in this

way at least on a temporary basis, if only for financial reasons. However, even a two-tier system may present certain difficulties, of which the agency should be aware.

Firstly, it has already been suggested that certain children who at present remain on the waiting-list indefinitely could be placed with professional carers. This would certainly involve children aged 11 or over including some who are non-ambulant; carers have also been reluctant to take hyperactive children. It is possible that, once established, the concept of 'hard to place' might be extended to cover other types of behaviour or condition or even certain 'types' of parents. The ability to provide a service to certain groups by placing them with professional carers would be a great advantage. However, there may be certain dangers. It could lead to decisions about placement being made on the basis of subjective value judgements; the study has shown how widely perceptions of a child's behaviour can differ, for example. It may result in a labelling process or in a negative focus on handicap and problems, rather than on individual personality and needs. It may create an element of stigma within part of the scheme or in the service as a whole. It may create selectivity, developments which have been successfully avoided to date. Conversely, there may be a danger that the voluntary part of the scheme would develop the image of being a second-class service, if, for example, these carers are known to receive less preparation, training and financial remuneration than professionals.

On the other hand, however, a similar diversification has taken place over recent years within the field of fostering, the various

strands apparently co-existing with relative ease. Triseliotis (1988a) has written:

Fostering is not about one thing but about a number of different types of caring involving different types of children. As a result, motivation and expectations can vary between placements ... there are traditional and professional or contract-type placements.
(p.17)

It seems likely that family-based respite care will develop along similar lines. The crucial task for social workers will then be to match family and carers whose motivations and expectations, needs and perceptions are compatible.

Implications for Practice

Preparation, Training and Support of Carers

Several recent studies of fostering have pointed to the importance of adequate preparation and support of foster parents (Cautley, 1980; Berridge and Cleaver, 1986). The same point has been made in relation to childminding (Bryant, Harris and Newton, 1980) and is strongly echoed here. The agency might like to consider whether it would not be a reasonable expectation that all potential carers should attend preparation sessions. The study showed that those with extensive previous experience found the meetings less helpful than did those without. It might therefore be advisable for the latter to attend an additional, initial session, which could introduce some basic concepts and information relevant to caring. Those with little or no experience of handicap are often concerned about epilepsy, for example, and other practical aspects of handling the children.

The preparation sessions which I attended as an observer made no allusion whatsoever to the issue of homesickness, identified as a major problem in several matches, nor to the special needs of under-fives. However, these issues are now covered as part of preparation. It should also be emphasised that children with profound or multiple handicaps are equally vulnerable to homesickness.

It would also seem useful for preparation sessions to include a full, but balanced, presentation of the types of demand and stress which different parents face in caring for their handicapped children. Similarly, it might be pointed out that no expectation exists that parents should pursue any special activities during periods of respite. Many derive most benefit from the unaccustomed opportunity of 'doing nothing'. Discussion along these lines might counteract signs of disapproval identified in one or two carers.

The practical aspects of preparation were generally considered most useful. It might therefore be helpful to give inexperienced carers the opportunity for more active participation in a local agency as part of their preparation, for example by undertaking some voluntary work at a local playgroup.

The importance should be stressed of the whole family being involved in preparation as far as possible. Again, the agency might consider organising one separate session for children, who could be encouraged to voice any worries they might have about the prospect of sharing their toys, bedrooms and/or parents with children whom they do not know. Social workers must ensure that carers have discussed the matter fully with their children, explaining as clearly as possible what will be involved. Particular attention should be paid to the reactions of under-fives.

Finally, at the introductory stage, carers should always make a visit to the family's home. Apart from facilitating the process of getting to know each other, this will enable carers to understand the child's familiar routines and environment. Such knowledge may be useful in helping the child settle in with their family.

The study has shown the need for a clear and consistent policy in relation to maintaining contact with and offering support to carers once the match gets underway. It is not safe to assume that because a particular match has proved problem-free in the past, it will continue to be so, nor that carers will automatically contact the agency when concerns do arise. It would therefore seem most important not only that regular reviews are made of all matches (as have been introduced since the fieldwork was completed) but also that contact is maintained with carers during the intervening periods. Robinson (1986) has suggested that social workers might make a point of visiting carers while the child is with them. This would ensure that carers have an opportunity to raise any matters of concern which might later be forgotten or considered not sufficiently important to justify 'bothering' the social worker. It would also allow the latter an opportunity to observe the interaction between carer and child and thus, a sounder base from which to offer support.

The role of groupwork as a vital tool in supporting foster and adoptive parents is currently emerging in that field of research (Triseliotis, 1988b). The present research showed considerable variation across the region in the frequency of carers' group meetings. While some respondents had attended several, others had been invited to none. The consensus of opinion suggests that these meetings should be held regularly, although not necessarily

frequently; the current norm of three or four times a year seems ideal. Again, some carers expressed little interest in attending such meetings, while others would have welcomed more. Consistency in practice and, ultimately, in the quality of service provided, suggests that all carers should be encouraged to attend whenever possible. There appeared to be some danger of the meetings becoming 'talking shops'. This might be avoided if an element of training was more deliberately introduced, which could cover specific practical tasks, such as learning Makaton, or First Aid, as well as talks given by external speakers on issues relevant to caring. The agency might also consider the value of holding training workshops on an occasional basis, perhaps focusing on subjects chosen by carers. Events of a specifically 'social' nature, could be organised separately.

The scheme has now introduced an informal 'carers' contract requesting, among other items, a two-year commitment to the service, with an option to renew. This procedure should give greater structure to the matches, allowing carers a 'legitimate' means of withdrawing, while also alerting parents to the reality that matches are subject to change over time.

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Preparation and Support of Parents

The findings suggest that greater attention should be paid to the preparation of parents before they join the scheme. In particular, there is a need for greater clarity among external professionals in assessing the appropriateness of making referrals to the service. As Oswin (1984) points out, it cannot be assumed that parents will welcome the prospect of a break from caring, especially if it involves separation from their child. The study has shown that

poor outcomes occur where families are referred to the scheme against their own inclinations. Those who are interested but ambivalent should be given ample opportunity to discuss their concerns: parents will not be able to prepare their children properly if they have been inadequately prepared themselves.

Social workers have an important task in distinguishing the levels of support appropriate to different families: there is a need for flexibility in this respect. For those who require more intensive support, social workers might act as catalysts, bringing parents and carers together to plan periods of respite in advance. It is most important, however, that social workers do not become involved as a third party in such negotiations unless asked to do so by parents. Regular home visits should continue to be made after and between match reviews.

The agency might give some thought to introducing a General Users' group, which could act as a forum for discussion about the scheme's operation, creating a clear channel of feedback to social workers. Alternatively, the agency might establish an informal management or steering group, consisting of both parents' and carers' representatives, along with practitioners and managers. Such a group could have a role in decision-making about policy matters.

Finally, the findings suggest that greater attention could be paid to families on the waiting-list. Systematic reviews of their cases should be made on a regular basis, and regular contacts maintained in order to update information and provide them with support. The agency might consider alternative sources of support to which these families could be referred while awaiting a carer, such as a sitting service, clubs or playgroups, residential provision or,

if appropriate, advice on welfare rights. Some may benefit from casework support: the likelihood of allocation within area teams is, however, low. A more realistic response would be to establish a support group for families on the waiting-list.

Older children especially those who are non-ambulant present a particular challenge in matching. While strong arguments exist against creating priorities as the basis of degree or type of disability, still it seems reasonable, indeed desirable, that some urgency be given to finding carers for families who have been waiting for several months.

Preparation and Support of Children

The agency might consider formulating some guidelines which would outline ways of reducing the incidence of severe homesickness and of responding to its symptoms. The quality of pre-placement preparation of children was inconsistent. Certainly, the form this takes will vary, depending on the ability of individual children and, perhaps, on their temperament. Parents are probably best placed to perform this task but, as mentioned earlier, their ability to do so effectively is likely to depend on the adequacy of their own preparation. Children should be told as clearly as possible about what is going to happen - with the visits to carers being presented as a treat. In some cases, it might be possible for parents to play simulation games with children, perhaps using dolls or toys to indicate they would be visiting friends and, most importantly, returning home again soon. In the case of children who tend to be excitable or who lack a sense of time, it would be preferable not to undertake preparation too far in advance. Parents themselves may be

the best judges of how to prepare their children but the agency has a responsibility to ensure that this has taken place.

Children with profound handicaps present a particular challenge in terms of preparation. For them, the best method may be a series of frequent, short visits to the carers, perhaps going for three or four hours several days in a row, during which time the carers could be encouraged to hold and touch the children, thus allowing the latter to become accustomed to the feel, sound, smell or sight of their new carers. It might also be helpful for the child to occupy the same chair or position in the room on each occasion so that she can become accustomed to its areas of light and darkness, shape, sounds and textures. In this way, she may gradually develop a sense of security in her new surroundings. Children always take familiar objects with them to the carers; perhaps their parents could also be encouraged to stay with them on more than the initial visit.

Irrespective of the child's level of handicap, it would seem important that the pace of the match be increased only gradually, unless exceptional circumstances prevail. It seems inadvisable for children to spend prolonged periods with carers during the early stages of a match. Nor, however, should visits become so infrequent as to prevent the child establishing a strong relationship with her carers. Social workers should be alert to any changes in patterns of use, particularly instances of 'under' or 'over-use'. Greater co-ordination with other agencies, particularly hospitals, would ensure that multiple use of respite facilities which may not be beneficial to the child, is quickly identified.

The agency might review the desirability of children joining the scheme within weeks or months of other events in their lives likely to unsettle them, such as starting school or the birth of a sibling. ✓

At present, the scheme lacks any clear policy on under-fives. Perhaps this age group should receive day-care for longer than is at present the norm, unless there are exceptional circumstances. Such visits could occur more frequently than is currently standard. Oswin's maxim that no care situation should be created for children with disabilities which would be considered abnormal for non-handicapped children, is a useful guideline.

Where children are unduly distressed by separation it has been helpful to stop overnight stays and revert to daycare, or for the carers simply to visit the child at home, without taking her out. Carers could also look after the child in her own home in the parents' absence, either for a few hours or overnight. Where children are distressed by 'handovers', the agency might review the practice of allowing them to travel to the carers by school transport. It is most important for parents to be open with their children. Whenever possible, children should be told in advance about the visits and arrangements adhered to. If parents feel unable to do this because their child is upset by the prospect of separation, then that is the issue which should be tackled, rather than exacerbated by avoidance. ✓

Finally, however, it should be acknowledged that some degree of homesickness is an inevitable aspect of respite care and will never be fully 'eliminated'. ✓

The Role of Share-the-Care in relation to other Services

The study identified certain families experiencing considerable stress who were not helped by family-based respite care. Such parents could be offered services which do not hinge on separation from the child, such as playgroups, home helps and other domiciliary support. Some who withdrew from the scheme were amenable to using daycare or a Befriending scheme. These findings suggest that home-based and daycare should be more readily available within the scheme. Indeed, to provide them under a different service, involving changes of caregiver if and when the child has overnight care, seems counterproductive.

Other families, however, will continue to prefer residential or institutional care. Sound arguments exist for developing small group homes to meet this need, but are outwith the scope of the present study.

It was suggested that socially-disadvantaged families might derive more benefit from the scheme if other material or practical supports were first made available. While it is beyond the remit of the scheme to tackle issues of social deprivation, yet workers might have a useful role in referring families to appropriate agencies such as the Housing Department, DHSS or grant-giving bodies.

Where parents felt great ambivalence towards the child or her future care, and where family interaction is seriously disturbed, referral to the scheme appeared to exacerbate stress. At the time of the children's birth or diagnosis, parents may benefit from Early Intervention counselling to facilitate the process of coming to terms with their feelings about having a handicapped child: it is believed that such intervention prevents the onset of defensive reactions and

maladaptive coping strategies, while facilitating future use of services (Cunningham, 1979). However, if contact with the scheme is these parents' first experience of social work support, then some input in the form of casework or even family therapy may be needed, if families are agreeable, before the usefulness of a referral to Share-the-Care is fully assessed.

It was noted that inappropriate referrals were sometimes made by externally-based workers, that some confusion existed between the roles and responsibilities of locally and centrally-based workers, and that some external professionals lacked a full knowledge and understanding of certain issues relating to the scheme, such as the capacity of children with severe handicap to feel homesick. Two possible solutions to these problems can be identified. The scheme could deploy its own workers in local area teams. One such appointment has recently been made, although intended to cover an entire division. A similar arrangement exists with Barnardo's Family Support Service in West Lothian. Social workers based in area teams would carry responsibility for informing other professionals about family-based respite care and involving them appropriately.

A second option would be to build on the good relationships already established with local special schools. It might be possible to expand areas of co-ordination with teaching staff, to use school premises for meetings, encourage parents to use the scheme or even recruit carers from among school staff. Several schemes in England operate successfully along these lines. Some parents may be more willing to consider using a service associated with the school, rather than the Social Work Department.

However, respite care is not sufficient within itself to meet all the needs of families who do use it successfully. The concept of self-determination for parents becomes meaningless if real choice is not available between a variety of services capable of responding to different needs and changing circumstances. Parents identified a number of gaps in existing local provision, such as holiday playschemes, 'key workers', a resource centre and, most importantly perhaps, family-based respite provision in the post-16 age group. Finally, there is a need for overall co-ordination of services to families with handicapped children, of which Share-the-Care should be only one part.

Implications for Future Research

Because the numbers involved in the present study are so small, it has been necessary at times to speculate on the implications of the findings rather than drawing any firm conclusions. As a result, a number of aspects of the research would benefit from more detailed examination using larger samples. However, eight particular areas can be identified as important priorities.

It was noted in Chapter 3 that the original plan for this study was to compare the experiences of parents using family-based respite care with those of a sample using hospital provision. To my knowledge, no such study has yet taken place, although Oswin (1984) has made a start in this direction. As respite care is becoming increasingly available within a variety of settings and more widely used, it seems most important to examine and compare the quality of care available in different resources, both from the parents' and, as far as possible, from the children's or clients' viewpoint. Such a study could include daycare provision in its remit, since this form

of support is more acceptable to some families than overnight care. Attention could also be paid to the views of planners and policy-makers, which were missing from the present study.

Secondly, there is a need for further research into the impact of respite care on the handicapped child's siblings and their reactions to the child's repeated departures from home. Such research should involve the siblings as direct informants. Similarly, the reactions and experiences of carers' children merit closer examination, again involving them directly in the research.

Thirdly, the concept of stress among respite carers has so far proved rather elusive. Robinson (1986) proposed to make such a study but was prevented from doing so by lack of evidence. Indications emerged in the present research that carers were susceptible to minor stress and strain, but the real extent and nature of this reaction remains unclear.

Fourthly, the study showed that older children, including those who are non-ambulant, and hyperactive children may be 'hard-to-place'. If respite care is to offer a flexible and universal service, then closer examination of this area is required, along with some exploration of possible responses to 'hard to place' children/families.

Fifthly, insufficient data was available from the present study to explore any link between parents' experiences at the time of birth and diagnosis and their subsequent ability (or inclination) to make effective use of the scheme. Recent research has shown that early intervention counselling may be crucial in facilitating parents to come to terms with their feelings about having a handicapped child

and, subsequently, to benefit from supportive services (Cunningham, 1979). Further research in this area would be useful.

Sixthly, it was speculated that socially disadvantaged families may benefit from the introduction of other practical or material supports before they will benefit from family-based respite care. Again, the numbers in the present study were too small to allow for any conclusions, but this is an issue which would repay further investigation, including some consideration of the type of supports which would be most effective.

Seventhly, in order to extend our understanding of the factors which contribute to the success or failure of placements, there is a need to identify more precise criteria according to which outcomes can be assessed and to refine the measuring tools for doing so.

Finally, in the course of the present study, it was often tempting to broaden the field of investigation to include a detailed examination of parents' broader coping strategies. Some research in this field has been completed (Pratt, 1976; Crinc, Friedrich and Greenberg, 1983). A fascinating area for future study would be the interaction of family-based respite care with different coping styles.

Summary and Conclusions

In conclusion, the study has shown that family-based respite care can be very successful in meeting the needs and expectations of a substantial proportion of families, both by strengthening their existing coping strategies and reducing levels of stress, in some cases apparently quite dramatically. Most parents identified a range of benefits to their children from using the service. With few exceptions, carers too derived great satisfaction from their

involvement in the scheme, encountering surprisingly few difficulties. Many parents, although not all, greatly preferred family-based respite care to residential or hospital provision. Thus, strong arguments exist for expanding the scheme to enable a larger number of families to benefit from it.

On the other hand, it has emerged that while the present semi-voluntary status of carers facilitates the process of sharing care for some parents, by enhancing their sense of security and trust in the situation, it may also act as a deterrent for others, by limiting their ability to exercise choice and control. It was suggested that the agency might consider operating a two-tier system of care, whereby the present 'caring hobby' contract remains unchanged, but a substantial number of professional salaried carers are also introduced. Certain difficulties which might accompany this development should be noted, however, such as the danger of creating elements of stigma or selectivity in the scheme.

The study shows a need to develop and strengthen the preparation and support of carers, parents and children alike. The desirability of tighter guidelines on homesickness and use of the scheme by under-fives should be emphasised. Regular, systematic reviews of the waiting-list are recommended. Finally, it cannot be assumed that all parents will necessarily welcome the prospect of a break from caring, especially if it involves separation from their child. Such parents should not be persuaded to join the scheme against their will. Rather, there is a need to develop a wide range of services for this client group, offering choice and flexibility to meet different needs. Ideally, family-based respite care should operate as just one service within a wide network of provision.

APPENDIX : QUESTIONNAIRES

QUESTIONNAIRE 1

CASE NO:

First Interview with Parents (prior to using the service)

Introduction: I think you already know that the reasons for doing this interview are that we want to find out how effective the Share-the-Care Scheme really is, and to see if what is being offered at present is what parents want. This interview is designed to find out about your circumstances now, before you start using Share-the-Care, and there will be a follow-up interview in 8-12 months time, to see if there have been any changes then. Everything you tell me will be treated confidentially and in no way will it effect the process of finding a family to care for your child. The final report will not mention any individual names or families. Is there anything you would like to ask me at this stage?

HUSBAND: Name

WIFE: Name

or SINGLE PARENT: Name

CHILD'S NAME:

SECTION 2 : Family Care of the Child

1. I would like to start by asking you a few questions about how you organise looking after X. Perhaps we could begin by discussing who in your household usually carries out various aspects of caring for X, although they may not all apply to him/her. Can you tell me, for each item, who is mainly responsible, who lends a hand, or whether it is fairly equally shared?

	Mostly mother	Mostly father	Sometimes siblings	Sometimes other	Shared	'Lend a hand'	N/A
--	------------------	------------------	-----------------------	--------------------	--------	------------------	-----

Feeding
Dressing
Washing
Toileting/or
 changing
 nappies
Playing
Driving/
 transport
Dealing with
 sleep
 disturbance
Watching/
 supervision
Making plans/
 arrangements
 (e.g. with
 school)

2. I wonder who normally does the following housework jobs? Can you tell me, for each item,
- (a) who is mainly responsible for them and usually carries them out;
 - (b) who lends a hand; or
 - (c) whether it is fairly equally shared?

Mainly responsible Lends a hand Shared

Cooking
Cleaning
Washing dishes
Washing clothes
Shopping
Minor household repairs

3. How many hours per day do you spend looking after X, **including keeping an eye on him/her?**

- (a) Virtually a 24 hour job
- (b) 15-24 hours
- (c) 8-15 hours
- (d) 4-8 hours
- (e) Under 4 hours

4. How far do you plan your daily routine around X?

If single parents, move on to No.7

5. How much time do you as a couple have to yourselves in a normal week? (specify)
6. How satisfactory is that?
7. How much time do you (each) have on your own in a normal week?

SECTION 3 : Social and Support Networks

Now I would like to move on to ask you about contacts you have with relatives, friends and neighbours and find out if they give you any help looking after X.

- 8. Is it ever difficult for you to go out on errands, for example, shopping or to the dentist?
- 9. (IF NOT EASY) Who do you call upon to help in that situation?
- 10. Who would you call upon in an emergency; for example, if one of you were alone in the house with X and you took ill suddenly?
- 11. Which of your relatives do you see regularly (if any)?
- 12. When did you last see them?

13. How far away do they live?
14. Do either you or they own a car?
15. (If not) How easy is it for you to see them?
16. Have they helped to look after X in any way over the last 12 months?
17. (If so) In what sort of ways and for what length of time?
18. Do you often visit friends, or invite them to your home?
19. When did that last happen?
20. Have any friends helped to look after X over the past 12 months?
21. (If so) In what sort of ways, and for what length of time?
22. Do you have much contact with your neighbours?
23. Have they helped you look after X in any way over the past 12 months?
24. (If so) In what specific ways, and for what length of time?
25. When did that last happen?
26. Can you tell me, looking back over this last fortnight, who all has helped you look after X in any way? (Check what way and for how long)
27. How satisfied are you with this amount of help?
28. How easy do you find it to ask other people to help you out?
 - (a) Very easy
 - (b) Easy
 - (c) Mixed feelings
 - (d) Difficult
 - (e) Very difficult

(Check why)
29. Do you find it easier to ask official organisations for help, or your friends and neighbours?

SECTION 4 : Family Social Life

I would like to move on now to some questions about your family social life.

30. How often do **you** go out (together if a couple) socially? Is it about
 - (a) Once a week
 - (b) Once a fortnight
 - (c) Once a month
 - (d) Once in three months
 - (e) Less than that
31. How satisfactory is that for you?
32. How often do you go out as a family, either socially or on an outing? Is it about
 - (a) Once a week
 - (b) Once a fortnight
 - (c) Once a month
 - (d) Once in three months
 - (e) Less than that
33. Have you had a holiday in the last year?
34. (If so) Who all went?
35. Where did you go?
36. How long did you stay there?
37. (If not) When did you last have a holiday?
38. Does X have friends and social activities outside the home?

SECTION 5 : Siblings (where appropriate)

Now I have a couple of questions about X's brothers and sisters (as appropriate).

39. How do they get along with X?
40. Do you think X's special needs have had any particular effects on their lives?
41. (If so) How have they reacted to that?

SECTION 6 : Effects of Parents' Work

We've had a look at some aspects of your family social life. Perhaps we could talk about your work now.

42. Has looking after X had any effects on your work or job prospects? (such as your hours and place of work)
43. (If so) How have you dealt with that?
44. (If appropriate) Would you both like to work?
45. Has having X prevented you from doing so?

SECTION 7 : Effects on Family Health/Finance

46. Moving on to family health now, besides X, have there been worries about anyone's health in the past 12 months?
47. (If so) What have you done about that?
48. Has any of the family been to see a doctor in the last 12 months?

(If so) May I ask why that was?

49. (If applicable) Do you think these complaints could be connected in any way to looking after X?
50. Do you think that looking after X has affected your own relationship in any ways?
51. If so, how have you coped with that?
52. Has bringing up X had any financial effects on you?
53. Do you or X receive any benefits or grants?
54. Finally, on this section, have you adapted or converted your house to suit X better?

SECTION 8 : Child Management

Now I'd like to look at some more general points about bringing up X and what sort of rewards and difficulties you have had.

55. First of all, what is it like bringing up a child like X? What are the first thoughts that come to mind?
56. Does his/her behaviour cause you any particular problems?
57. If so, how do you cope with that?

- 58. What sort of rules do you set him/her?
- 59. Is there any time of the day or night which is particularly difficult for you?
- 60. What sort of rewards and pleasures has X brought you?

SECTION 9 : Social Work Support

I wonder if we could move on now to some questions about any assistance you may have had from a social worker. Again I'd like to stress that whatever you tell me will be treated confidentially.

- 61. Do you have a social worker, or have you had one in the past?
(If so, move on to No.66)
- 62. (If not at all) Is that because you don't want or need one?
(If yes, move on to Section 10)
- 63. (If social work contact has ceased) How long did you have a social worker for?
- 64. Why did that finish?

ASK THE FOLLOWING QUESTIONS IN RETROSPECT

- 65. How often do you ('did you') see him/her?
- 66. What sort of assistance has she/he given you? (Specify)
- 67. Do you think your social worker understands your situation?
- 68. Would you say she/he is:
 - (a) Very helpful
 - (b) Helpful
 - (c) Mixed
 - (d) Not very helpful
 - (e) No help at all

SECTION 10 : Contact with other Professionals

69. Can you tell me if you have had contact with any of the following professionals about X in the last 12 months?

Professional	Any contact	How regular	Any special issue
--------------	-------------	-------------	-------------------

Teacher			
G P			
Consultant			
Nurse			
Health Visitor			
Physiotherapist			
Speech therapist			
Psychologist			
Home Visitor			
Other			

70. What do you think about the contacts you've had with these professionals? How helpful have they been?

71. Where would you say you get most of your support from?

SECTION 11 : Services Used

Now I would like to talk about some of the services you may have used.

72. Have you ever used any of the following?

- (a) Local Authority nurseries
- (b) Children's centres
- (c) School clubs
- (d) Voluntary organisations

73. and

- (a) Home help
- (b) Care attendant
- (c) Special aids and equipment
- (d) Laundry service
- (e) Other (specify)

74. How easy did you find it to get hold of these services?

75. Do they provide enough help for you and X?

76. Do you belong to any parents' group?

SECTION 12 : Previous Separation Experiences

77. Has X ever been away from you overnight?
78. (If not) Is there any special reason why she/he hasn't?
79. (If so) Can you tell me

Source	Frequency	Average length of stay	Rate of satisfaction	Reasons for dissatisfaction
--------	-----------	---------------------------	-------------------------	--------------------------------

- (a)
(b)
(c)
(d)
-

80. What were the main reasons for X going to?
Was it:

- (a) For medical reasons
(b) To give you a break
(c) To give X a holiday
(d) Due to some emergency/crisis
(e) Some other reasons (specify)

81. How did X react to being away from you?
82. How did you react to being separated from him/her?

SECTION 13 : Application to Share-the-Care

83. When did you first hear about the scheme?
84. How did you hear about it?
85. What was your reaction to the idea then?
86. (If applicable) Were both of you equally interested?
87. (If not) Has that caused any difficulties?
88. What did you think of the child profile? Did it allow you to give as much information about X as you wanted to?
89. What appealed to you about Share-the-Care in particular?
90. Do you think the Share-the-Care social worker understands what you want from the scheme?

91. When were you told they were actively looking for carers for X?
92. How happy are you with the timing of the whole process from your first enquiry through to the stage you are at now?
93. How happy are you with the way your application has been handled? Do you think anything should have been done differently?

SECTION 14 : Expectations about using Share-the-Care

Finally, the last section covers your expectations about using Share-the-Care

94. How often would you like X to go to carers?
95. For what length of time?
96. What sort of qualities do you think carers need?
97. What sort of people would you like to see as X's carers? (e.g. age, social background, married/single)
98. How do you think another family will get on looking after X?
99. How easy do you think you will find it to hand X over to someone else to look after?
100. Can you describe how you feel at this stage about the application?
101. What will you do when she/he is with carers?
102. What differences do you think Share-the-Care might make in your lives?
103. Do you think Share-the-Care might affect X's future in any way?
104. As a final question, is there anything you would like to ask me?

QUESTIONNAIRE 2

CASE NO:

Second Interview with Parents

HUSBAND'S NAME:

WIFE'S NAME:

or SINGLE PARENT:

CHILD'S NAME:

CARER'S NAME:

CARER'S CODE NO:

LENGTH OF PLACEMENTS:

FREQUENCY OF PLACEMENTS:

NUMBER OF PLACEMENTS:

SECTION 1 : General View of Share-the-Care

1. First of all, can you tell me if there have been any major changes for you since we last met, such as a new baby, a change of job, or something like that?
2. You've been using Share-the-Care for some time now. How's it been going? (Probe)
3. Has it turned out as you expected?
4. Is that how you both feel?
5. Has it made any differences in your lives? (Probe)
6. Has it made any differences to X? (Probe)
7. Has it made any differences to X's brothers and sisters? (Probe)
8. What do you do when X is with Mr and Mrs ...?

SECTION 2 : Leisure, Work, Health and Relationships

(Some questions picking up on the first interview)

9. Since we last met, have there been any important changes in the services you're using, any you've stopped or any new ones started?
10. Have there been any significant changes in the professionals you have contact with - teachers, doctors, therapists or social worker?
11. What about help from relatives, neighbours or friends? Has that increased or decreased in any way? (Probe)
12. Where do you get most of your support from?
13. How much time do you have together as a couple in an average week?
14. How much time do you (each) have on your own in an average week?
15. How often do you go out together socially?
 - (a) Once a week
 - (b) Once a fortnight
 - (c) Once a month
 - (d) Once every three months
 - (e) Less than that
16. Have you had a holiday since I last interviewed you?
17. How long for?
18. Would you say you have more or less time to yourselves now?
19. Last time you spoke about your work, you said ...
Have there been any changes there?
20. And when you talked about your health, you mentioned ...
Would you say that has got better or worse or is it about the same?
21. Has having Share-the-Care made any differences to your own relationship?

Going on to X now:

22. Have there been any changes for him/her, perhaps a new school or a new club, he/she's going to? (Probe)
23. Does his/her behaviour cause any particular problems just now? (If applicable, 'Last time you mentioned ...')
24. (If so) How do you cope with that?
25. Is there any time of the day or night which is more difficult for you than others?

SECTION 3 : Practical Arrangements about Share-the-Care

26. How happy were you with the timing of the whole process, from your first enquiry about Share-the-Care through to when X was placed with carers?
27. How happy were you with the way your application was handled generally? (Probe)
28. How much choice did you have about who was to be your carer?
29. Were you satisfied with that amount of choice?
30. What did you think about the way the introduction to the carers was arranged? (Probe)
31. Do **you** normally contact the carers to arrange for X to go and stay with them?
32. How easy do/would you find it to ask them? (Probe)
33. What prompts you to ask for a break?
34. Do the carers ever contact you to suggest X goes to visit them?
35. Have they ever been unable to have X when you wanted them to?
36. (If so) How did you feel about that?
37. Are you satisfied with this way of making arrangements?
38. Would there be any benefit in having a social worker involved?
39. Are you happy with the amount of breaks you get through Share-the-Care?

SECTION 4 : The Child

40. Does X enjoy going to the carers?
41. How do you tell? How does he/she show his/her feelings?
42. Did you try to explain to him/her what was happening when he/she first went there?
43. Do you think he/she understands what's happening?
44. How easy did you find it to part with X the first time he/she went there?
45. Do you still feel the same way?
46. (If applicable) What makes it difficult?
47. How do you find it not having X around?
48. How well would you say X has settled down with the carers?
49. Do you think he/she ever feels homesick?
50. How do/would you tell if he/she was?
51. (If applicable) Does he/she ever refer to the carers when he/she is at home? (Probe)
52. Have you noticed any differences in X's behaviour since he/she started going to the carers?

SECTION 5 : The Carers ('reminder about confidentiality')

53. How well do you know Mr and Mrs ...?
54. Do you talk with them about X much?
55. How easy do you find that?
56. How well do you think they cope looking after X?
57. Do you think they treat him/her in the same sort of ways as you do, or are there any differences? (Probe)
58. Are you aware of any important differences between your two families which might affect the match? (Probe)
59. Have you ever felt unhappy about the care X receives at the carers' house?

60. How do you see the carers? Are they like:

- (a) Family friends
- (b) Childminders
- (c) Auntie/Uncle for X
- (d) Something else

SECTION 6 : Contact with Share-the-Care Social Workers

61. Do you have contact with the social worker on a regular basis?

62. How useful is that for you?

63. Do you feel the social worker understands what you want from Share-the-Care?

64. Do you think there would be any point in having some sort of Share-the-Care parents' group to go to?

(If so) What sort of group would you find useful?

65. Do you think parents have enough say in Share-the-Care?

SECTION 8 : Other Sources of Respite Care

66. Are you using any other sources of respite care? (Probe)

67. How would you say Share-the-Care compares with them, or with places you've used in the past? (Why?)

SECTION 9 : The Future and Overall Perceptions

68. Do you intend to carry on using Share-the-Care in the foreseeable future?

69. (If not) Why not?

70. What would you do if Share-the-Care closed down?

71. What are the best things about Share-the-Care?

72. What are the drawbacks?

73. Would you recommend the scheme to other parents?

74. Are there any changes or developments you'd like to see in it?

75. How satisfied are you with the service?

- (a) Very satisfied
- (b) Satisfied
- (c) Mixed feelings
- (d) Dissatisfied
- (e) Very dissatisfied

76. That's all the questions I have, unless you want to add anything or ask me anything.

Date of interview

Length of interview

Taped/not taped

Those interviewed

Other comments

QUESTIONNAIRE 3

CASE NO:

Carers' Interview

Husband

Wife

Single person

Name of matched child/ren

SECTION 2 : Finding Out About Share-the-Care

1. How did you first hear about Share-the-Care?
2. When was that?
3. What was your first reaction to the idea?
4. Did you follow it up straightaway, or did you think it over for a while?
5. (If applicable) Were you both equally interested in becoming carers?
6. (If not) Is that still the case?
7. (If so) Has that led to any difficulties?
8. Did you discuss the idea with your children?
9. What was their reaction?

SECTION 3 : Motivation

10. Have you ever been involved in fostering?
11. Have you ever been involved in voluntary work?
12. Had you had any previous contact with people with mental handicap?
13. (If 'yes') What sort of contact?
14. (If 'no') What did you know about handicapped children?

15. What would you say were your main reasons for wanting to become carers?
16. Did you have any particular type of child in mind who you wanted to look after, in terms of age, size, ability etc.?
17. What did you feel you could offer a child?
18. I wonder if you could tell me who usually does the following household jobs. Can you say for each item
 - (i) who is mainly responsible and usually carries it out;
 - (ii) who lends a hand; or
 - (iii) whether it is fairly equally shared?

	Mainly responsible	Lends a hand	Shared
--	--------------------	--------------	--------

Cooking			
Cleaning			
Washing dishes			
Washing clothes			
Shopping			
Minor household repairs			

SECTION 4 : The Preparation Sessions

19. Can you remember how many preparation sessions you went to?
20. Did you find there were too many sessions, too few, or was it about right?
21. What sort of subjects did they cover?
22. Did you learn much from them? (Check what)
23. Looking back, do you think any important topics were left out or not fully covered?
24. Would you have any advice for people planning future sessions?

SECTION 5 : Introductions to Child and Family

25. Was X the first child you were introduced to?
If 'yes' Move on to No.29
If 'no'
26. Can you tell me what happened before you met X?

27. Why do you think that happened?
28. How did you feel about it?
(Going back to X now)
29. What information were you given about X before you met him/her?
30. Were you shown a copy of his/her 'child profile'?
31. Did that give you a clear idea of what looking after X would be like?
32. Can you tell me how you first met X and his/her parents?
33. How did you build up your meetings from there to the time when X first stayed with you?
34. What did you think about the way these introductions went?
35. Did you have any particular concerns about looking after X at that stage?
36. Were you happy with the timing of the whole process, from your first enquiry about Share-the-Care up to X's first stay with you?

SECTION 6 : Practical Arrangements about Visits

37. How many times has X been to stay with you?
38. Is there a set pattern for visits, such as the last weekend in every month, or does it vary?
39. How long does she/he usually spend with you?
40. Have you ever looked after X at his/her home?
41. Do X's parents usually contact you to arrange a visit?
42. Do you ever contact them to suggest a visit?
43. Are you satisfied with this way of making arrangements?
44. Would there be any benefit in 'the social worker' being involved?
45. Have you ever been unable to have X when his/her parents wanted you to? (Check why)
46. (If so) How did you feel about that?

47. Have you ever agreed to have X when you would rather not have done?
48. (If so) How did you feel about that?
49. How near do you live to the X's? (Check specific distance)
50. How does X get to and from your house?
51. What do you normally do with X during his/her visits?
52. (If applicable) Do your own children get involved in looking after X or playing with him/her?
53. Have you had problems in any of the following areas?
(Check what problems)
 - Aids and equipment
(Have you received any)
 - Access to/inside your house
 - Lifting X
 - Medical problems
 - Any other
54. (If so) How have you tackled these problems?
55. Have there been any emergencies? (Check what)
56. Who would you contact if X was taken ill suddenly?

57. I wonder who is responsible for some of the practical aspects of looking after X when she/he's with you. If I mention a few, could you tell me for each item
- (i) who is mainly responsible;
 - (ii) who lends a hand; or
 - (iii) whether it is fairly equally shared?

Mostly wife	Mostly husband	Sometimes children	Shared	Lends a hand
----------------	-------------------	-----------------------	--------	-----------------

Feeding
Dressing
Washing
Toileting or
changing nappies
Playing
Driving/transport
Dealing with
sleep disturbance
Watching/
supervision
Making plans/
arrangements

SECTION 7 : Rewards and Drawbacks

58. What would you say are the best things about being carers?
59. What are the drawbacks?
60. Do you think that being carers has made any differences in your family, or had any particular effects?
61. A lot of parents who are looking after a mentally handicapped child at home full-time feel that they are under a good deal of pressure. Do you ever feel like that when X is with you?
62. (If so) How do you cope with that?
63. How have your friends and neighbours, or other members of your family, reacted to you being carers?

SECTION 8 : The Child

64. Do you think X understands what's happening when she/he comes to stay with you? (Check why)
65. Does she/he fit in with your normal family routine?
66. Have you changed your routine to suit X better?
67. How long did it take him/her to settle down with you?

68. Have you noticed any signs of homesickness?
69. Does his/her behaviour cause you any particular problems?
70. (If so) How do you cope with that?
71. What sort of rules do you set him/her?
72. Is there any time of the day or night which is particularly difficult?
73. I wonder how you see yourselves in relation to X? (Probe: Is it like friends, aunt and uncle, childminders, something else?)

SECTION 9 : The Parents

74. How well do you know Mr and Mrs ...?
75. Do you talk about X with them much?
76. Do you think you treat X in the same sort of way as they do, or are there any differences?
77. Do you think Mr and Mrs ... find it hard to 'let go' of X when she/he comes to you?
78. (If so) How have you responded to that?
79. Are you aware of any differences in your home situation and lifestyle from theirs?
80. (If so) Has that had any effect on the match?
81. Do you feel they value the part you play as X's carers?
82. Do you know if having breaks through Share-the-Care has made any differences to them?

SECTION 10 : Contact with Share-the-Care Social Workers

83. How often do you have contact with 'the social worker'?
84. What sort of contact? Is it by letter, phone calls, home visits?
85. How useful is that contact for you?
86. Have you ever needed to contact him/her for any special reasons, besides routine matters? (Check what)
87. Do you feel that she/he values the part you play as carers?

88. How do you see your relationship with him/her? Is he/she an organiser, colleague, supervisor, source of information or something else?

SECTION 11 : Carers' Group Meetings

89. Do you go to these meetings?
90. (If not) Why not?
91. (If so) How often?
92. What is the point of these meetings?
93. How useful do you find them?
94. Are there any changes you would like to see in these groups?

SECTION 12 : Carers' Payments

95. What would you say is the purpose of paying carers?
96. Do you find the payment adequate, less than adequate or more than adequate?
97. And the system of making payments: does it work?

SECTION 13 : General View of Scheme and Future Plans

98. What do you see as the main purpose of Share-the-Care?
99. Are there any changes or developments you would like to see in it?
100. Do you intend to carry on as carers in the foreseeable future?
101. (If not) Why not?
102. How easy would you find it to withdraw from Share-the-Care?
(Check why)
103. How do you see your role as carers? Is it a spare-time interest only, or would you be interested in it as a part-time job, if that became possible?
104. Would you be prepared to have a child for more than 6 weeks a year?
105. (If so) For how long, approximately?
106. Would you be prepared to take more than one child?
107. Finally, is there anything you would like to add, or anything you would like to ask me?

QUESTIONNAIRE 4

CASE NO:

Questionnaire for Parents on the Waiting-List
(later adapted for parents who withdrew)

Husband's name

Wife's name

Single parent

Child's name

Date of first interview

Date of second interview

Date of application

Length of waiting

SECTION 1 : Contact with Share-the-Care Scheme

1. It's several months since you applied to Share-the-Care. What sort of contact have you had from the Share-the-Care social workers since then? (e.g. letters, phone calls, visits)
2. (If applicable) What have you heard from your own social worker about your application?
3. Has he/she introduced you to any possible carers, or suggested an introduction? (If 'no', go on to Q.7)
4. (If applicable) Can you tell me what happened?
5. (If applicable) Why do you think that fell through?
6. (If applicable) What was your reaction to that?
7. Have you contacted the social worker at all to enquire about your application?
8. (If not) Is there any special reason why you haven't done so?
9. Who would you contact if you wanted to make an enquiry about your application? (go on to Q.13)
10. (If so) What exactly did you enquire about?

11. What was the outcome?
12. How satisfied were you with that?
13. Why do you think you've had to wait this long?
14. Has the social worker given you a reason? (Probe)
15. Do you know what is happening to your application now?
16. How long would you say is reasonable to wait for carers?
17. Were you warned it might take as long as this?
18. How happy are you with the way your application has been handled overall?
19. Can you suggest anything which should have been done differently?
20. Has your attitude towards the scheme changed in any way since you first applied?

SECTION 2 : Other Sources of Respite Care

21. Has X stayed away from home overnight since our first interview?
(If not, go on to Q.27)
22. (If so) Where has he/she stayed?
23. For how long?
24. How satisfied are you with these arrangements?
25. Does he/she ever show any distress about going away, or when he/she comes home? (Probe)
26. Would he/she still stay at if you were also using Share-the-Care? (Go on to Q.29)
27. (If not) Have you tried to find any alternative to Share-the-care? (Probe)

SECTION 3 : Topics Covered in First Interview

28. Have there been any important changes for you since the last interview, such as the birth of a new baby or a change of job?
29. Have there been any changes in services you're using, anything you've stopped using, or new ones started?
30. Have there been any changes in the professionals you have contact with, teachers, doctors, therapists or social workers?
31. How regularly do you see your social worker?
32. What about help from relatives, neighbours or friends. Has that increased or decreased in any way?
33. Have there been any changes in your social lives; for example, do you go out more in the evenings, or do you have less time to yourself?
34. Have you had a holiday since I last met you?
35. (If so) For how long?
36. Last time you spoke about your work, you said
Have there been any changes there?
37. And when you talked about your health, you mentioned
Would you say that has got better or worse or is it about the same? How much better/worse?
38. Have you noticed any difference in family relationships, in how you get on together?
39. Going on to X now.
Have there been any changes for him/her, maybe a new school or a new club he/she's going to?
40. Does his/her behaviour cause any particular problems just now?
(If applicable, 'Last time you mentioned ...')
41. (If so) How do you cope with that?
42. Is there any time of the day or night which is more difficult than others?

SECTION 4 : Perceived Effects of Waiting for the Service

43. How has it effected you, having to wait several months for carers?
44. Do you think, if you were using Share-the-Care, it could have made any differences to you (the parents)?

45. Do you think it could have made any differences to X?
46. Could it have made any differences to X's brothers and sisters?
47. Last time we met, you said you hoped Share-the-Care might
Are you still concerned about that?
48. Have you found other ways of handling/easing that situation?
49. Do you feel the same need for Share-the-Care as when you first applied?
 - (a) More need
 - (b) About the same
 - (c) Less need
50. Is there anything else you'd like to add?

Those present:

Length of interview:

Taped/not taped:

Comments:

QUESTIONNAIRE 5

Parents who Withdrew after using the Scheme

Topics for Discussion

Breakdown of the Match

1. Perhaps you could tell me what's happened since we last met?
At that stage, you were ...
2. Whose decision was it to stop?
3. (If applicable) Was it a difficult decision?
4. (If applicable) Was it mutual?
5. (If applicable) Did anyone try to change your mind?
6. Was it a 'planned' ending, or sudden?
7. How did you react to it falling through?
8. Was it not what you expected?
9. Did you have misgivings from the start?
10. What were the positives?
11. In retrospect, what do you think were the main reasons for it falling through?
12. What would have needed to be different, to make it work?
13. Have you ever regretted the decision?

The Child

14. How did X get on with the carers?
15. Did she/he enjoy going to visit them?
16. What did she/he do there?
17. Did your child benefit from going to carers?
18. What feedback did you get from X?

19. Was X homesick?
20. If so, how was that handled?
21. Was there any change in child's behaviour after she/he first started going to carers?
22. How did X react to the arrangement finishing?
23. How did you explain the situation to X?
24. Does she/he understand?
25. Does she/he ever refer to carers now?

The Family

26. How did X's brothers and sisters react to X going to carers?
27. What did the family do while X was away?
28. How easy did you find it to part with X?
29. How did you feel about X being away from home?
30. Have there been any important changes in the family since the first research interview? (e.g. change of job, new baby)

The Carers

31. How much choice did you have in carers?
32. How did the introductions go?
33. Were they the sort of people you had expected?
34. Did you visit the carers' home? If so, was it suitable?
35. How were arrangements made for visits?
36. Who contacted whom?
37. How easy did you find it to ask for a break?
38. Did arrangements work out OK?
39. Were carers ever unable to look after X when you wanted them to?
40. Did you talk to the carers about X much?

41. Did they treat X in the same sort of way or were there any differences?
42. Were you aware of any difference in their lifestyle from yours' or in the way they ran their home?
43. Did the carers enjoy X's visits?
44. How well do you think the carers coped looking after X?
45. Did you tell the carers of their decision?
46. Did you discuss it together?
47. Did the carers feel the same way? (that the match wasn't working)

~~Share-the-Care Workers~~

48. How happy were you with the way the application was handled?
49. How helpful was the social worker generally?
50. Did she/he understand what you wanted?
51. At what point did you tell the social worker of your concerns?
52. Was the social worker involved in the decision to stop?
53. How did she/he react?
54. Did the social worker suggest any alternatives?
55. Would parents be interested in another care under ~~Share-the-Care~~?
56. Have you withdrawn from the scheme altogether?

Use of Other Services

57. Do you still feel a need for short-term care?
(If applicable) More, less or about the same as when you first applied?
58. Are you using any other sources of respite?
59. (If so) How do these compare to ~~Share-the-Care~~?
60. How happy are you with them?
61. How happy is the child?

62. Any homesickness?
63. (If not) Have you tried to find other alternatives?
64. Any changes in services you are using?
65. Any changes in help from friends, relatives?
66. Do you have any suggestions about how to help prevent breakdown in matches?

QUESTIONNAIRE 6

CASE NO:

Placement Breakdown

Topics for Discussion with Carers

Breakdown of the Match

1. Perhaps you could tell me what happened in your match with Mr and Mrs ...?
2. Whose decision was it to stop?
3. (If applicable) Who told you of the decision?
4. What did you make of it?
5. What was your reaction?
6. Was it a 'planned' ending, or sudden?
7. How did you feel about it falling through?
8. What were the positives?
9. In retrospect, what do you think were the main reasons for it not working out?
10. What would have needed to be different to make it work?

The Child

11. What did you all do together?
12. Did she/he fit into the family routine?
13. How did the carers enjoy having X to visit?
14. How well did X settle down?
15. Was she/he homesick?
16. If so, how was that handled?
17. Any problem areas, like difficult behaviour? If so, how was that coped with?
18. Did the carers notice any changes in X's behaviour over time?
19. How did their own children react to X being around?
20. Do the carers' children understand why X stopped coming?

21. Did the carers get a chance to say goodbye to X?

Child's Parents

22. How did the introductions go?
23. Did you have any concerns about looking after X at that stage?
24. How much choice were you given about the child you were matched to?
25. Did you visit the parents' home?
26. How easy did X's parents find it to part with the him/her?
27. How were arrangements made for visits?
28. Who contacted whom?
29. How successful were these arrangements?
30. Did parents find it easy to ask you to take X?
31. Were you ever unable to have X when the parents asked?
32. Did you talk to the parents about X much?
33. Did you treat X in the same sort of ways, or are there any differences?
34. Were you aware of any differences in lifestyle or the way they ran their home?
35. Any contact since?

Social Worker

36. Did social workers discuss the situation with you?
37. How helpful was that?
38. Did the social worker suggest placing another child with you?
39. (If so) How soon after?
40. Do/did you want to take another child?
41. Was the possibility of matches not working out discussed at preparation sessions?
42. Has this experience altered your view of the scheme in any way?

SCHEDULE 1

CASE NO:

Personal Information about Children and Family Background
Collected from Agency Records

1. Case number [...]
2. Child's sex : Boy 1 [...]
Girl 2
3. Year of child's birth (two integers) [...]
4. Part of the Region : Edinburgh 1 [...]
West Lothian 2
Midlothian 3
East Lothian 4
Elsewhere 8
5. Type of area : City 1 [...]
Town 2
Rural 3
6. Parents' marital status :
Together 1 [...]
Divorced/separated 2
Widowed 3
Single (alone and never married) 4
Other 8
Not known 9
7. Whom child lives with :
Both parents 1 [...]
Mother only 2
Father only 3
Reconstituted family 4
Foster/adoptive parents 5
Grandparents 6
Other 8
Not known 9
8. Number of siblings [...]

9. Child's place in family :

Only child	1	[...]
First child	2	
Middle	3	
Last	4	
Twin	5	
Not known	8	

10. Handicapped siblings :

Yes	1	[...]
No	2	
Not known	8	

11. Occupational class of husband :

Professional	1	[...]
Managerial	2	
Skilled non-manual	3	
Skilled manual	4	
Semi-skilled	5	
Unskilled	6	
Unemployed	7	
Not known	9	

12. Occupational class of wife :

Professional	1	[...]
Managerial	2	
Skilled non-manual	3	
Skilled manual	4	
Semi-skilled	5	
Unskilled	6	
Unemployed	7	
Not known	9	

13. Tenure of dwelling :

Owner-occupied	1	[...]
Local authority	2	
Privately rented	3	
Tied	4	
Housing association	5	
Other	8	
Not known	9	

14. School child attends :

Willowbrae	1	[...]
Beatlie	2	
Westerlead	3	
Westfield	4	
St Crispin's	5	
Nursery school	6	
Not yet at school	7	
Other	8	
Not known	9	

15. Diagnosis :

Down's Syndrome	1	[...]
Cerebral palsy	2	
Hydrocephaly/spina bifida	3	
No firm diagnosis	4	
Other	8	
Not known	9	

16. Child's mobility :

Few or no problems	1	[...]
Limited/some difficulty	2	
Very limited/none	3	
Not known	9	

17. Child's speech :

Few or no problems	1	[...]
Limited/some difficulty	2	
Very limited/none	3	
Not known	9	

18. Child's continence :

Few or no problems	1	[...]
Limited/some difficulty	2	
Very limited/none	3	
Not known	9	

19. Epilepsy :

Yes	1	[...]
Controlled	2	
None	3	
Not known	9	

20. Recurrent infections :

Yes	1	[...]
No	2	
Not known	9	

21. Physical handicap :

Severe	1	[...]
Mild/moderate	2	
None	3	
Not known	9	

22. Medical condition :

Severe	1	[...]
Mild/moderate	2	
None	3	
Not known	9	

23. Child's hearing :

Few or no problems	1	[...]
Limited/some difficulty	2	
Very limited/none	3	
Not known	9	

24. Sight :

Few or no problems	1	[...]
Limited/some difficulty	2	
Very limited/none	3	
Not known	9	

25. Medication :

Yes	1	[...]
No	2	
Sometimes	3	
Not known	9	

26. Significant behavioural problems :

No great problems	1	[...]
Extreme passivity	2	
Hyperactive/aggressive/ destructive	3	
Some difficulty	4	
Other	8	
Not known	9	

27. Method of communications :

Speech	1	[...]
Sign language/gestures	2	
Sounds only	3	
Other	8	
Not known	9	

28. Can child feed self :

Yes	1	[...]
With help	2	
No	3	
Not known	9	

29. Can child dress self :

Yes	1	[...]
With help	2	
No	3	
Not known	9	

30. Can child wash self :

Yes	1	[...]
With help	2	
No	3	
Not known	9	

31. Can child toilet self :

Yes	1	[...]
With help	2	
No	3	
Not known	9	

32. Supervision required :

Constant	1	[...]
Extensive	2	
Limited	3	
Not known	9	

33. Source of referral :

Area team	1	[...]
G P	2	
Hospital	3	
School	4	
Health visitor	5	
Self referral	6	
Voluntary organisations	7	
Other	8	
Not known	9	

SCHEDULE 2

Personal Information about Carers Obtained from Agency Records

1. Case Number [...]
2. Marital status/relationship :

Married couple	1	[...]
Cohabiting couple	2	
Separated/divorced/ widowed woman	3	
Single woman	4	
Other	5	
3. Wife's year of birth : 2 integers [...]
4. Husband's year of birth : 2 integers [...]
5. Part of the Region :

Edinburgh	1	[...]
West Lothian	2	
Midlothian	3	
East Lothian	4	
Elsewhere	8	
6. Type of area :

City	1	[...]
Town	2	
Rural	3	
7. Wife's occupational status :

Professional	1	[...]
Managerial	2	
Skilled non-manual	3	
Skilled manual	4	
Semi-skilled	5	
Unskilled	6	
Unemployed	7	
Not known	9	

8. Husband's occupational status :

Professional	1	[...]
Managerial	2	
Skilled non-manual	3	
Skilled manual	4	
Semi-skilled	5	
Unskilled	6	
Unemployed	7	
Not known	9	

9. Did wife state her occupation as 'housewife/mother :

Yes	1	[...]
No	2	
Not known	9	

10. Wife's religion :

Protestant	1	[...]
Catholic	2	
Christian	3	
Other		
None	4	
Not known	9	

11. Husband's religion :

Protestant	1	[...]
Catholic	2	
Christian	3	
Other		
None	4	
Not known	9	

12. Type of dwelling :

Detached	1	[...]
Semi-detached	2	
Bungalow	3	
Flat	4	
Maisonette	5	
Other	8	
Not known	9	

13. Tenure :

Owner-occupied	1	[...]
Local authority	2	
Privately rented	3	
Tied	4	
Housing association	5	
Other	8	
Not known	9	

14. Is playspace available :

Yes	1	[...]
No	2	
Not known	9	

15. Does access involve stairs :

Yes	1	[...]
No	2	
Not known	9	

16. Bus within 10 minutes walk :

Yes	1	[...]
No	2	
Not known	9	

17. Is bathroom downstairs :

Yes	1	[...]
No	2	
Not known	9	

18. Do carers have a car :

Yes	1	[...]
No	2	
Sometimes	3	
Not known	9	

19. Number of children in family [...]

20. Adopted/fostered children :

Yes	1	[...]
No	2	
Not known	9	

- | | | |
|--|---|-------|
| 21. Number aged 0-5 years | | [...] |
| 22. Number aged 6-12 | | [...] |
| 23. Number aged 13-18 | | [...] |
| 24. Number aged 19+ | | [...] |
| 25. Own children handicapped : | | |
| Yes | 1 | [...] |
| No | 2 | |
| Not known | 9 | |
| 26. Number of children placed through scheme | | [...] |

POSTAL QUESTIONNAIRE FOR REFERRING AGENCIES

CASE NO:

SECTION 1 : The Families

1. How many families have you referred to Share-the-Care? [...]
2. How long did you know these families prior to their application?
3. Why did you refer them to Share-the-Care?
4. How keen were they to be referred?
5. How many are you actively involved with now, on issues other than Share-the-Care? [...]
6. Do you think there may be an unmet need for social work support in any of these families (on issues other than Share-the-Care)?
7. Have you found that families need ongoing support in their use of the scheme?
8. (If so) In your view, whose responsibility is it to provide that support?
9. How often do you have contact with them about their use of the scheme?
10. Briefly, what are the main issues you have come across in relation to parents' use of the scheme?
11. What sort of differences (if any) do you think Share-the-Care has made to these families?
12. How far has it achieved the aim you/they had in mind when applying?
13. How do parents feel about being recipients of a social work service?
14. What support can be given to families who have to wait a long time for carers?
15. In what sort of circumstances would you decide **against** referring a family to Share-the-Care?

SECTION 2 : The Carers

16. What sort of contacts do you have with carers?
(If 'none', please go on to Section 3)
17. Have you found that carers need ongoing support?
18. (If so) Whose responsibility is it to support carers?
19. Briefly, what are the main issues which have arisen in relation to carers and caring?
20. How do you monitor the quality of care provided?

SECTION 3 : The Children

21. What preparation do children have before they go to carers?
22. What are the main issues you have come across in relation to childrens' use of the scheme?
23. What differences (if any) do you think Share-the-Care has made to the children?
24. Do you think they ever feel homesick?
25. How do/would you deal with a child's homesickness?
26. What sort of children do you think might be unsuitable for Share-the-Care?
27. How would you respond to parents who wanted Share-the-Care for a child aged under 5?

SECTION 4 : The Central Share-the-Care Team

28. How much contact do you have with the scheme organisers?
29. Have you been given sufficient factual information about the scheme? (Delete as appropriate)

YES NO
30. Were you given sufficient guidelines about how to operate the scheme yourself, e.g. how to prepare families, assess carers etc.?

YES NO
31. How clear is the division of tasks and roles between yourself and the Share-the-Care organisers?

SECTION 5 : Your Own Agency

32. How much priority does your agency give to Share-the-Care?

SECTION 6 : Other Forms of Respite Care

33. What other forms of respite care have your clients used, in the last year?
34. In your opinion, how do these compare with Share-the-Care?

SECTION 7 : General Perceptions of Share-the-Care

35. What do you see as the main purpose of the scheme?
36. How do you see it fitting into other types of service provision for mentally handicapped children and their families?
37. What would you say are the main advantages of the scheme as it operates now?
38. What are the disadvantages?
39. Are there any changes or developments you'd like to see in it?

Thank you very much for answering these questions.
If you have any comments to add, please do so below.

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